

# PALESTINE CARITAS BABY HOSPITAL PROJECT

The Institute of Clinical Bioethics at Saint Joseph's University

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Caritas Baby Hospital, Bethlehem, Palestine, is founded in 1952 by Swiss priest Father Ernst Schnydrig and now sponsored by the Franciscan Sisters of Padua, Italy. It is the charity hospital which provides care for almost 40,000 children on the West Bank and in Gaza, many of whom are refugees. In August 2016, the Institute of Clinical Bioethics (ICB) has agreed to serve as the hospital's bioethics team. We believe that our affiliation with the

Caritas enlivens Saint Joseph's Jesuit mission and gives us the opportunity to respond to Pope Francis' call to reach out to refugees.

This new project opens new avenues of research for SJU undergraduate and graduate students, particularly an opportunity to develop a deeper understanding of both Jewish and Muslim perspectives on bioethics. Apart from the research, the ICB will provide clinical ethical consultancy as well as ethics education for physicians, nurses, medical residents, and staff via online tools (e.g., Skpye and Piazza) during regular semesters and on-campus visits during summer. The concrete contents of this project is as follows:

1. To engage in research with the Caritas' medical professionals and the ICB's facilities and fellows.
2. To help formulate and initiate various ethics policies which can be implemented in the hospital's own cultural contexts.
3. To provide ethics consults when requested.
4. To help develop the hospital's ethics committees.
5. To render clinical ethical opinions to the ethics committee as committee members.
6. To help develop the hospital's academic committee.
7. To develop and design ethics course curriculum - All lectures and courses will be provided through "e-Learning" system developed on the ICB website.

8. To deliver lectures to physicians, nurses, medical residents, and staff via online and on-campus visits.

## CURRENT RESEARCH

### "To Treat or Not to Treat: The Case of Methylmalonic Acidemia"

Across the globe, neonatal medical care is becoming more accessible to mothers and their infants while advances in care technologies continue to extend the range of treatment options for medical professionals. For this reason, many newborns are treated aggressively with new medical regimens, dynamic surgeries, and other life-prolonging measures. Included in these neonates are many that, in the past, would not have survived past infancy due to complex medical complications such as genetic defects, premature births and low birth-weights, and other disadvantageous abnormalities. Judgements on who is to receive aggressive treatments have yet to be standardized with a widely accessible moral criterion, and as a result, many neonates with potentially lethal genetic disorders have been the recipients of such treatments. Previously, some of these neonates would have been allowed to die; however, for some, the treatments do prove successful. For many others, the life-prolonging outcomes are in opposition with many ethical and moral analyses of the best interests of the neonate. For this reason, there are conflicts when decisions need to be made about specific newborns with genetic disorders such as methylmalonic acidemia (MMA). Methylmalonic acidemia is a recessive genetic disorder in which there is a complete or partial deficiency of the enzyme methylmalonyl-CoA mutase or a defect in the transport or synthesis of its cofactors which results in an increase of organic acids in the body when proteins are ingested. The organic acids overwhelm the neonate causing severe ketoacidosis, hypotonia, hyperammonemia, neutropenia, and thrombocytopenia (Manoli et al.). MMA is a major concern in countries such as Palestine where immediate family members marry and have children that inherit MMA at a much higher rate than neonates in western countries. Inter-marriages decrease the size of the local gene pool, which results in a higher inheritance rate of recessive disorders. Much research has been completed on MMA; however, literature is lacking a consensus on treatment protocols and has only fabricated recommendations specific to the condition that do not account for cultural issues in Palestine. Richard McCormick, a revised natural-law ethicist has produced a quality-of-life criterion that can be used to evaluate treatment options for neonates born with MMA. This criterion assumes a middle position that accounts for the best interests of the patient. Evolving from McCormick's criterion are Peter Clark's five moral-conscious treatment categories for neonates. These five categories along with McCormick's breakthrough moral criterion will be central to this article. The aims of this article are to present a case of a Palestinian neonate born with acute methylmalonic acidemia, apply McCormick's criterion to this specific case of MMA and to Peter Clark's S.J. five diagnostic treatment categories, and lastly generate a concise conclusion considering cultural dispositions to aid decision-makers in similar situations when deciding whether to treat or not to treat cases of methylmalonic acidemia.