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Latin American consensus on the supportive care of patients suspected or diagnosed with SCID before curative treatment

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Background: Severe Combined Immunodeficiency (SCID) is lethal without treatment. Hematopoietic stem-cell transplantation (HSCT) and gene therapy represent the only way to rescue the phenotype and cure the patient. Developed countries diagnose more and earlier SCID and are able to carry HSCT within 3 months in the majority of their patients. Latin American countries represent part of the developing world were diagnosis and treatment are severely delayed maximizing vulnerability and negatively affecting clinical outcomes in patients with SCID. Supportive care is crucial in order to keep patients alive and in fit status to receive definitive treatment. Clinical scenario of patients from Latin America are very different from developed countries and require specific interventions, which to the best of our knowledge is very heterogeneous between different countries.

Objective: Provide a practical guideline for supportive treatment based in consensus from experienced immunologists in Latin America.

Methods: We performed an extensive literature review and asked for advice and local guidelines from experienced immunologists at specialized centers from USA, Canada, Italy, England, France, Sweden, Germany, Argentina, Brazil and Colombia) to develop a list including all the supportive and general treatment measures for SCID patients. We then developed a consensus via modified-Delphi technique to agree on the pertinence of applying such interventions within the context of Latin America reality.

Results: We developed a final document consisting of 86 agreed diagnostic and therapeutic interventions grouped in 8 domains (i.e. protective isolation; antimicrobial prophylaxis, intravenous human immunoglobulin replacement; immunizations; nutritional interventions; infections and antimicrobial treatments; use of blood-products; laboratory work-up; imaging and other studies; multisciplnary work).

Conclusions: This is the first document that tries to homogenate clinical decisions in the diagnosis and treatment of SCID patients in the context of Latin America reality. We think this will serve to give a starting point to analyse and develop further improvements in the care of such vulnerable patients. This document is useful not only for immunologists, but also primary care physicians and other specialists involved in care for SCID patients.

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