

Political analysis of the neonatal screening for severe combined immunodeficiency - Curitiba, Brazil

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Severe Combined Immunodeficiency (SCID) is the most aggressive form of primary immunodeficiencies, being able to death within 2 years after birth. In the USA, the screening found that the incidence of SCID was double that previously stipulated, before screening. Israel, Taiwan, Spain and others European countries are also testing for SCID. The long-term survival of patients diagnosed and treated before 4 months of life reaches 94%. Brazil does not perform neonatal screening for SCID through the Public Health System (SUS), numbers are unknown and under-diagnosed, even the treatment for

SCID is funded by SUS. Analyze the political dimensions of the bill that aims to implement neonatal screening for SCID in Curitiba, Brazil. Participatory research was carried out between March - October 2019 and, bibliographic research on policy analysis in the context of emerging countries, to understand the criteria are taken into account for the political agenda, the influence of interest groups and the influence of the political arena in the implementation of a public policy through policy analysis. The project is pending in the municipal legislature of Curitiba and faces issues related to the financing of the implementation - a wide range of dependent variables act in the construction of a public policy. Its materialization, although important for public health, must consider real possibilities of implementation. In parallel, independent of the bill, a screening pilot project is under preparation by doctors, academics, and civil society. Brazil has a feasible technique that can be implemented on a large scale for neonatal SCID screening. However, although strongly recommended by the medical community, the implementation of this policy can be unviable by political and financial issues.

Key messages:

- The implementation of a public policy involves decisions between institutions, rules of the game and political forces.
- Early diagnosis may reduce treatment costs, requiring public policies for SCID.