Building a National Program on Inherited Bleeding disorders in Brazil

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BACKGROUND

Inherited bleeding disorders (IBD) are heterogeneous group of rare diseases characterized by bleeding manifestations of variable severity. IBD require treatment for life, which is complex and costly. Mostly, treatment requires intravenous infusion of factor concentrates (FC) and/or blood products at prophylactic and/or episodic basis.

THE BEGINNING

The population of patients with IBD increased nearly 200% from 2002 to 2018 (Fig. 1). This resulted from policies targeting on education of personnel working in the hemophilia treatment centers (HTC), diagnostic laboratories, production of guidance documents and teaching activities. Therefore, currently, Brazil has now the fourth world population of patients with hemophilia (PWH)1.

The implementation of several policies in the IBD program has improved health outcomes, such as decreased mortality (Fig. 5), reduced prevalence of inhibitors and hemophilic arthropathy. Currently, about 400 PHA were included in ITI with a success rate of 74%

AIM

The aim of this presentation is to describe the process and outcomes of the Program of IBD of the Ministry of Health (MoH) in Brazil, since 2004.

OUTCOMES

TREATMENT

To treat these patients, policies such as revision of the tender, prices and distribution of FC to the HTCs were installed (Fig. 3). This later enabled the purchase of more quantities and implementation of home therapy, hemophilia prophylaxis and immune tolerance (ITI) for hemophilia A from 2012 and also, treatment of all rare IBD.

REFERENCES