

ACCOMPANIMENT SYSTEMATIZATION OF PATIENTS WITH INHERITED METABOLIC DISEASE BY AN NGO – INSTITUTO CANGURU – IN BRAZIL..

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The Instituto Canguru (IC) is a NGO established in 2002, in Brazil, whose main mission is to disseminate knowledge of inherited metabolic diseases (IMD) among health professionals and society in general, proposing initiatives in order to facilitate the access of patients to information and necessary treatments to deal with the disease. Our objectives:

- Publish information about IMD to health professionals and to population in general
- Propose initiatives that facilitate access of IMD patients to laboratory tests necessary for the diagnostic investigation and clinical follow up.
- Provide legal support to IMD patients in order to facilitate their access to proper treatments
- Survey nationwide data about IMD.

In these 5 years about to abide by our mission and objectives, many campaigns have been created and they had generated a register of families and patients with IMD. Appearing here of a demand about to accompaniment from them. We initiate therefore a systematization to accompaniment, with the creation of collect data file card than it is to is fills in on a quarterly basis by contact telephony with the relatives of the patients, and relate biannual by health services, responsible for treatment of patients in your country.

Thus we start the controls above the application of diet, medical foods and medicines that had been gotten through from the IC of the instructions to done to the responsible health services.

As soon avoiding than it is to may get any wasted, along use inadequate as of products, since the one acquisition of these by the government must be a right used inclusive for it to may be utilize this data about to reinforcement from the necessitous as of politics publishes specifies in this sanded.