

## **PRELIMINAR DATA OF FOLLOW-UP CAMPAIGN IN PATIENTS WITH AN INHERITED METABOLIC DISEASE AT THE INSTITUTO CANGURU**

Renata Bernardes de Oliveira<sup>1</sup>, Beatriz Jurkiewicz Frangipani<sup>1</sup>, Tânia Vertemati<sup>1</sup>, Carla Aline Satiro<sup>1</sup>, Soraya Araujo<sup>1</sup>, Helena Pimentel<sup>1</sup>, Efigenia Leite<sup>1</sup>, Eugenia Valadares<sup>1</sup>, Carolina Souza<sup>1</sup>, Roberto Giugliani<sup>1</sup>, Salmo Raskin<sup>1</sup>, Luis Santana<sup>1</sup>, Ana Maria Martins<sup>1</sup>, Cecília Micheletti<sup>1</sup>

**INTRODUCTION:** The Instituto Canguru (IC) is a NGO established in Brazil; its main mission is to disseminate knowledge of inherited metabolic diseases among health professionals and society in general, proposing initiatives to facilitate patient access to information and the necessary treatments.

**OBJECTIVE:** Describe the preliminary data to follow up the patients assisted by IC.

**METHODS** – files were used to collect all information previously elaborated and tested. Information were collect by telephone. In this first round a group of disease were selected according to the complexity of its treatment. Patients with MSUD were selected.

**RESULTS** – Twenty and two registered patients, 3 died, 9 can not be located by the Institute and 10 of them gave us the necessary information. Among these 2 responsible people for these patients related theirs difficult in dealing with the diet. But all of them followed the diet without break the diet and visiting the Institute on the scheduled day and time. All theirs answers were according the expectation for the treatment for MSUD.

**CONCLUSION:** The importance of this study is to follow-up the accompaniment keeping the IC informed about data of patients treatment who had received our care , avoiding wasting of products that most of times were supplied by government or through donations , all with high cost. Also the patients with regular support of health professional have lower difficult in following their diet. These patients showed us how important is to maintain the campaign to up date the information





