

English Title:	PRELIMINARY RESULTS FROM A CAMPAIGN OF YEAR FOLLOW-UP OF PATIENTS WITH PHENYLKETONURIA.
English abstract:	<p>INTRODUCTION: Canguru Institute has the mission of to spread knowledge of hereditary metabolic diseases (DMH) through health professionals and society in general, facilitating the patient access to information and treatment. Considering this, a lot of campaigns were created generating registry of patients. Consequently, we had a demand for monitoring. We elaborate forms to collect informations and these forms are filled by responsible of patients by phone and analysed by the doctors and nutritionists team from IC to verify the need for actions to facilitate the treatment. In Brazil the phenylketonuria is diagnosed and treated in the reference centers that integrate the program of neonatal screening.</p> <p>OBJECTIVE: To describe the results from the campaign of year follow-up of patients with phenylketonuria previously registered.</p> <p>METHODS: Forms were used to collect the information previously developed and tested. The informations were collected by phone with the patient responsible. At each step we select a group of disease to update and consequent fulfillment of the objectives of the campaign.</p> <p>RESULTS: Of the 67 patients contacted, 25 with late diagnosis, 63 reported regular returns to the center of reference and membership in the dietary treatment. In all questions of knowledge about the disease and diet, most of the responses was consistent with the treatment for people with phenylketonuria. Only half of respondents reported some difficulty in dietary management, but 65 proposed actions that would facilitate adherence to treatment.</p> <p>CONCLUSION: The importance of this monitoring keeping the informed IC of patients questions, directs actions to fulfill our mission.</p>
Authors:	Oliveira, RB(1), Vertemati T(1), Satiro CA (1) , Viana SP (1), Araujo S (1), B J Frangipani, BJ (1), Pimentel, H (1), Leite, E (1), Valadares, E (1), Giugliani, R(1)1, Raskin S(1), Silva, LS (1), Martins, AM (1), Micheletti, C (1).
Institutions:	1 – Instituto Canguru
Spanish Title:	
Spanish abstract:	