

# DATA ANALYSIS RELATED TO THE WORK CARRIED OUT BY A BRAZILIAN NGO WITH HEALTH PROFESSIONALS AND PATIENTS WITH INHERITED METABOLIC DISEASES

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**BACKGROUND:** The Brazilian NGO, Instituto Canguru, disseminates knowledge on Inherited Metabolic Diseases (IMD) among health professionals and society in general. **OBJECTIVES:** Data analysis regarding the work carried out by Instituto Canguru with health professionals and IMD patients and families. **METHODS:** The attendance to health professionals and patients' families was carried out through a call free and email services. A registration was done on patients, parents, relatives, health professionals and associations. Instituto Canguru has implemented a Brazilian Nationwide Mapping Campaign on IMD, whose objective was collecting data on patients, health services and a diagnosis campaign with partners in charge of laboratory diagnostic analyses. **RESULTS:** Data regarding contacts until April 2008: 1127 health professionals, being: 557 Physicians, 422 Dieticians, 10 Phonoaudiologists, 22 Physiotherapists and 116 other professionals. 2249 patients and their families registered, being: 1263 parents (733 mothers and 530 fathers), 24 relatives and 962 patients, who were registered by other persons. Aside these, 267 made contact for IMD suspicion and entered to the Diagnosis Campaign; 35 other diseases' bearers also did contact and were directed to other associations for necessary assistance. **CONCLUSIONS:** The analyzed data demonstrate the necessity and importance of organizations to provide information and support to IMD diagnosis and treatment, due the lack of knowledge observed among health professionals and society in general



