

IMPORTANCE OF INFORMATION SPREAD ON INHERITED METABOLIC DISEASES FOR DIETICIANS

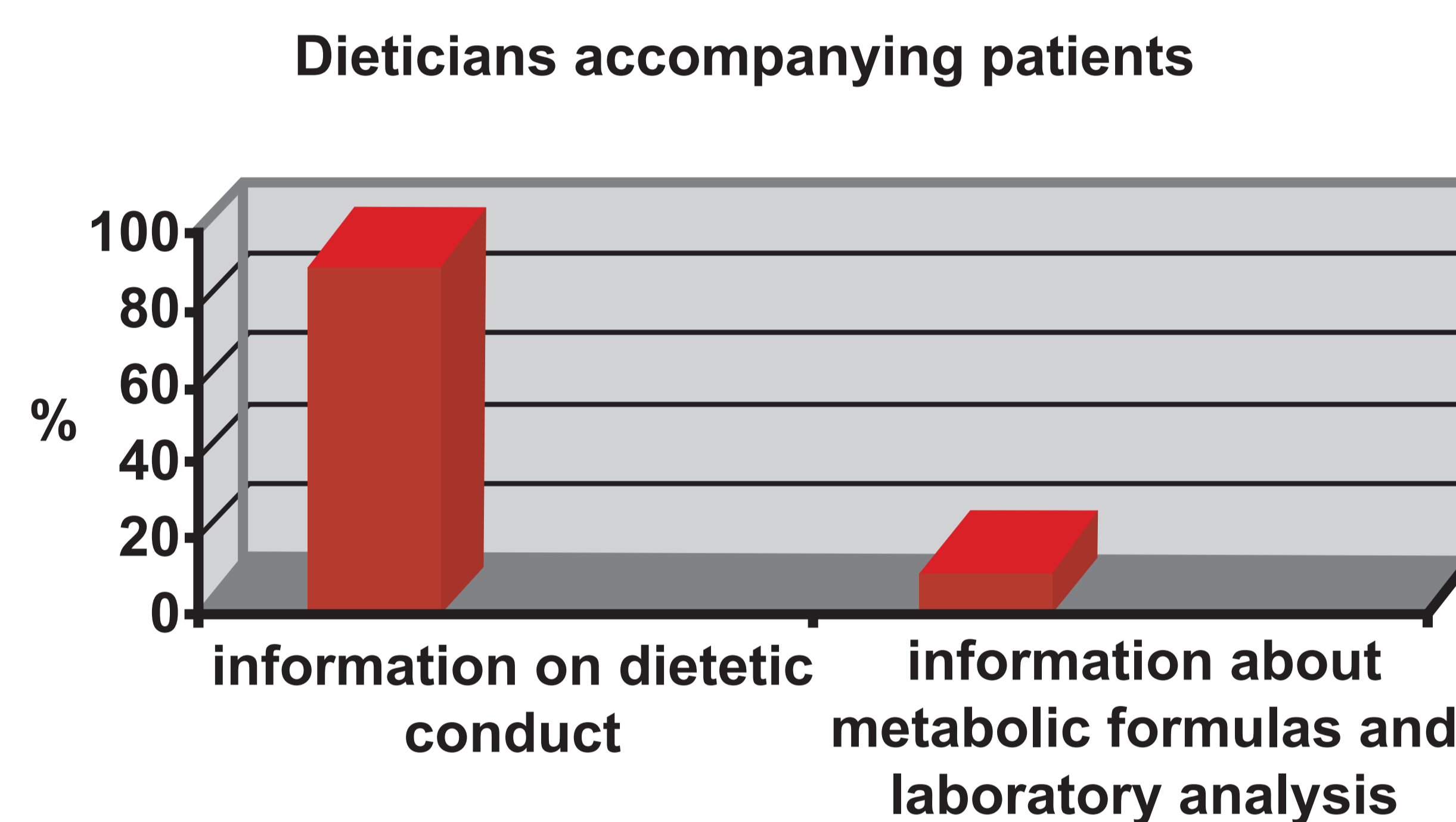
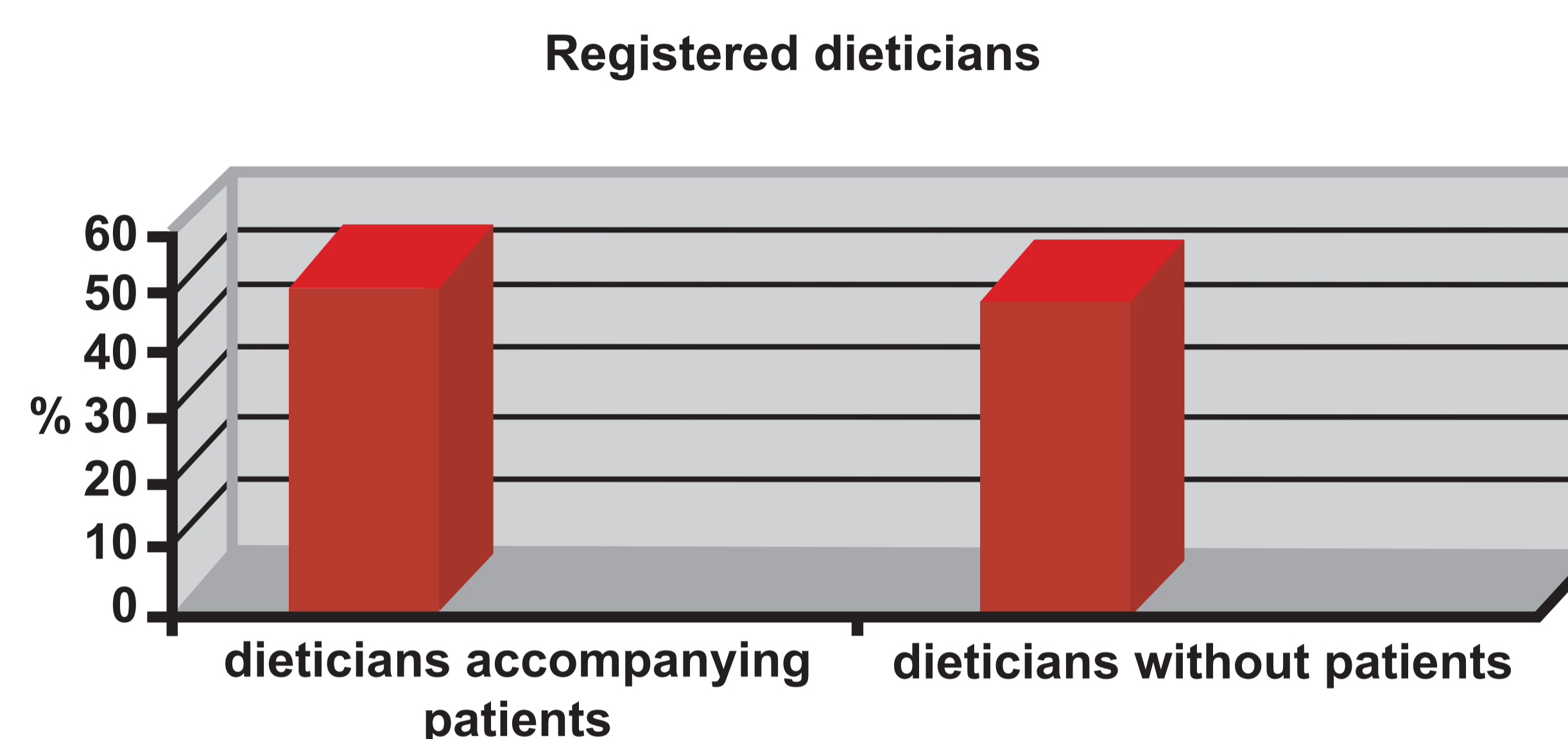
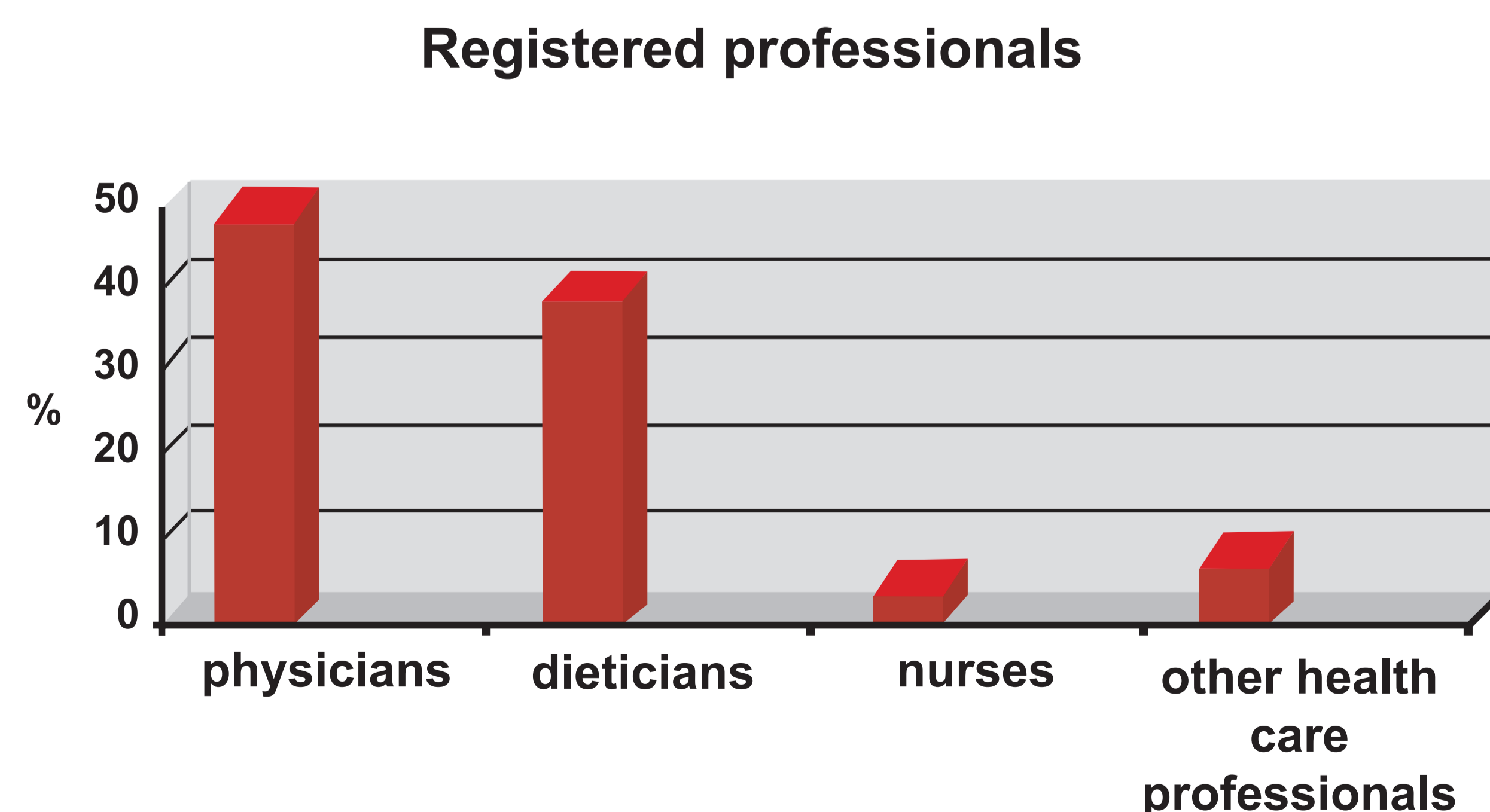
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BACKGROUND: "Instituto Canguru" is a Brazilian NGO, whose mission is disseminating knowledge related to Inherited Metabolic Diseases (IMD) among health professionals and society in general, making easier diagnosis and appropriate treatment. IMD are individually rare and little known by dieticians, emphasizing the importance of dietetic intervention to avoid severe consequences of these diseases.

OBJECTIVES: Identify doubts presented by dieticians who contacted "Instituto Canguru".

METHODS: To accomplish its mission, "Instituto Canguru" has been developing its activities highlighting the attendance to health care professionals through a call free and email services. At first contact, professionals are registered and directed to the technical team (geneticists and dieticians). Data were obtained in our own databases from May 2005 to April 2008.

RESULTS: During the evaluation time 422 dieticians were registered: 51% of them were accompanying diagnosed patients in their respective services. Among them, 90% got in touch due unknowing on dietetic conduct to be implemented and 10% were searching for information about metabolic formulas and laboratory analysis. 49% didn't refer being accompanying IMD patients. 39% asked for information and bibliographic references and 61% were registered in congresses and other events.



FINAL CONSIDERATIONS: The results demonstrate an elevated lack of knowledge on IMD dietetic conducts, however, was observed interest of dieticians on information and appropriate conduct on dietetic intervention. Thus, we believe in the importance of organizations in dissemination of IMD knowledge, since precocious and appropriate introduction of convenient diet can avoid serious sequel in patients.



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. Certain ignorance about IMD was observed in the most of the attended cases.

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.

Fig. 2 Health Professional contact IC

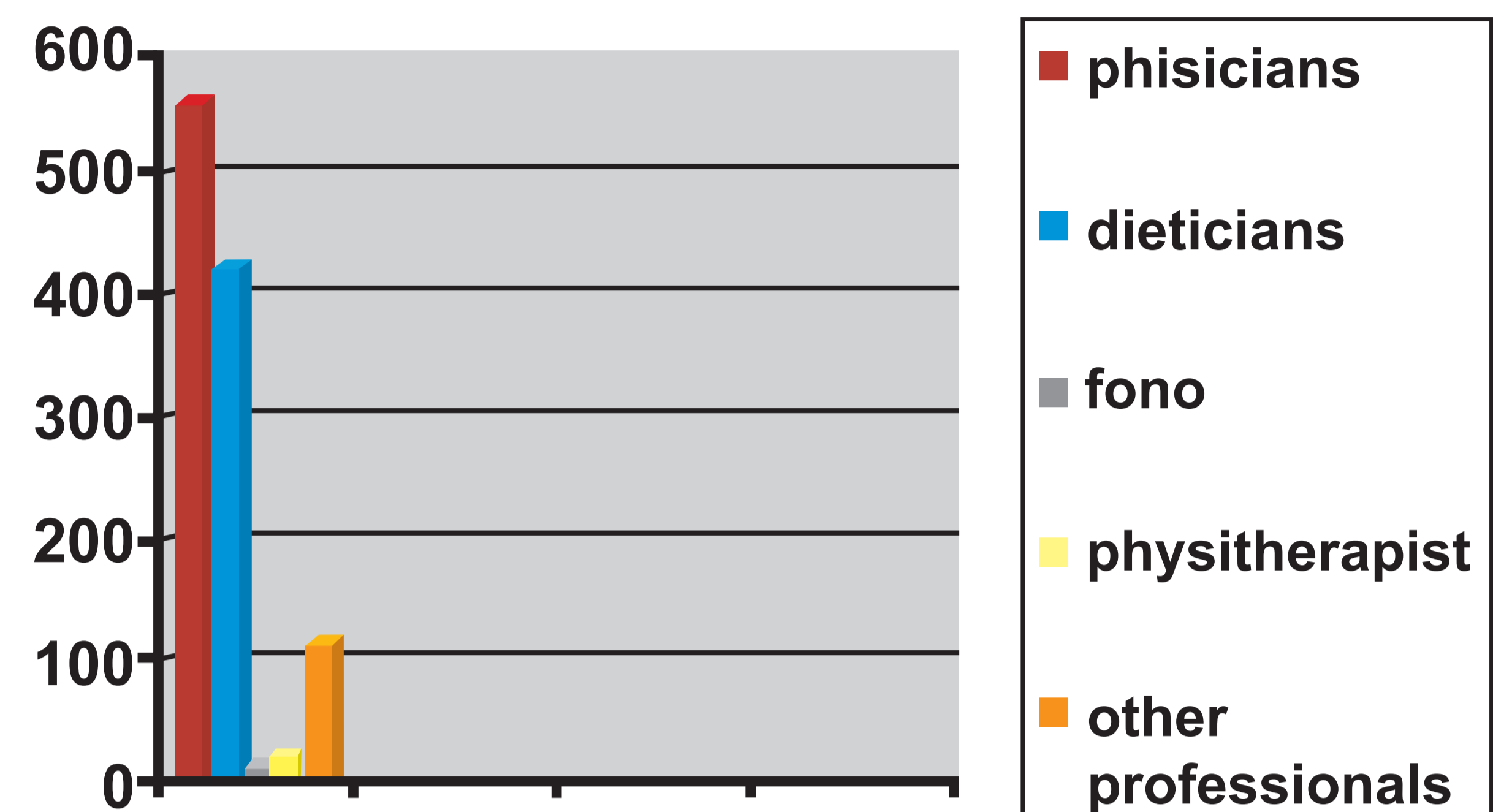


Fig. 3 Family contact IC

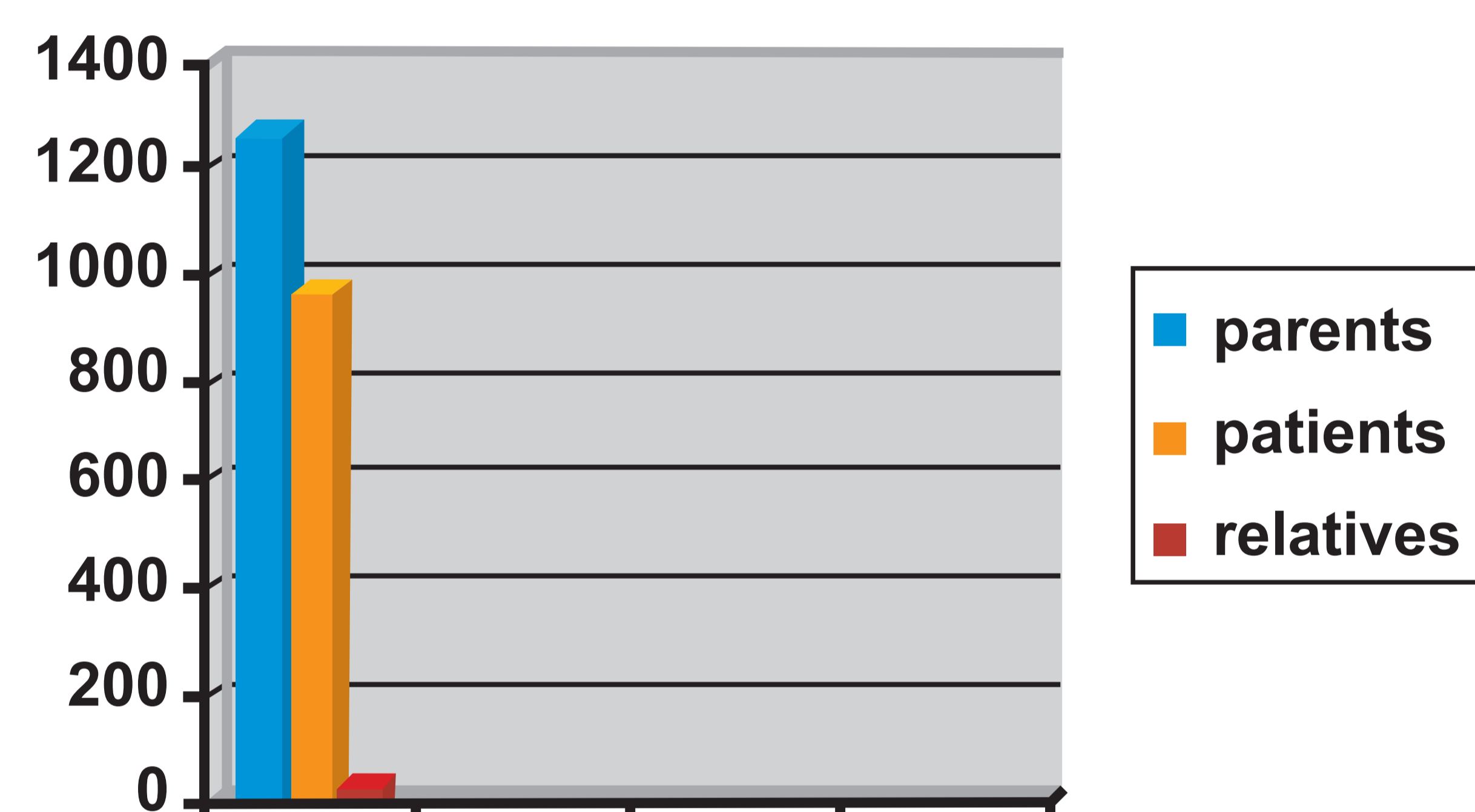


Fig. 1 Contacts of IC

