

RESULTS OF ASSESSMENT TO THE PRO NATIONAL RARE DISEASE AND ORPHAN DRUGS CONGRESS MEETING IN BRAZIL

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Introduction: The initiative to structure a DR net and launch the First Brazilian DR Congress started with GEISER Foundation – the first non profile organization in Latin America to focus on the health and live conditions for DR patients, and its representatives in Brazil, Instituto Canguru (IC), whose proposal is to inform and share the Inborn Errors of Metabolism(IEM) knowledge, proposing initiatives to facilitate the access of patients to diagnosis and necessary treatment.

In order to organize this Meeting and a future Congress, these entities joined the Instituto de Genética e Erros Inatos do Metabolismo (IGEIM), a ONG that supports patients with EIM. And contribution for organization - the Associação Brasileira de Ataxias Hereditárias e Adquiridas(ABAHE), and Aliança Brasileira de Genética (ABG); led by them, other associations related to DR, members from the pharmaceutical industry, health professionals and govern representatives were invited to join the Meeting.

Objective: inform the RESULTS OF ASSESSMENT of our Meeting

Methodology: The evaluation was performed with a questionnaire distributed to all participants

Results: We have 147 participants in these meeting, but 143 forms received and accounted, supporting the results below:

1- In your opinion, the First Pró-Congress Meeting was: -very good (60%) - good (40%)

1. The agenda reached your expectations: - totally (63%) - Partially (31%).

2. Positive aspects: - Topics presented (29%) – debates (19%) – Information actualization (15%) – patients and associations presence (15%)

3. Negative Aspects: Patients and associations presence (23%) – general audience response (19%) – debates (14%) – knowledge of national conditions (14%) – Patients and associations involvement (15%)

4. Topics suggested for the Congress: information access- DR access to all (17%) – Health Plans and DR (15%) – Informed consent form (14%) – DR patients support (14%) – DR network overview (13%)

Conclusion: DR and orphan drugs knowledge in Brazil is restrict and it is important to increase patients' relatives and associations, government, universities and pharmaceutical industry into a higher involvement and discussion on country perspectives and future actions. To count on international organizations experience to improve our conditions would be a way to speed this process.