

English Title:	PERSPECTIVE OF A NETWORK OF RARE DISEASES IN BRAZIL
English abstract:	<p>The GEISER Foundation , first non profile organization in Latin America to focus on the health and live conditions for Rare Disease (RD) patients, design one delegate into the Brazil. what is administrator of the Instituto Canguru (IC). On 2008 those groups they started training from a net of DR into Brazil wherefore the nation he may be acquainted from the organizations international of RD, to invited the Instituto de Genetica e Erros Inatos do Metabolismo (IGEIM) and support of another entities on realization by first meet RD in Brazil. We are invited members from the pharmaceutical industry, health professionals and govern representatives</p> <p>Objective: inform the results of assessment for meeting</p> <p>Methodology: The evaluation was performed with a questionnaire distributed to all participants.</p> <p>Results: We have 147 participants on meeting, supporting the results below:</p> <p>1- In your opinion, the First Pró-Congress Meeting was: very good (60%), and good (40%).</p> <p>2 Positive aspects: Topics presented (29%), discussions (19%) , information actualization (15%) , patients and associations presence (15%).</p> <p>3 Negative aspects: association's presence (23%), general audience response (19%), association's involvement (15%).</p> <p>4 Topics suggested for an Congress: information access (17%), Health Plans and RD (15%).</p> <p>Conclusion: RD knowledge in Brazil is restrict and it is important to increase patients' relatives and associations, government, universities and pharmaceutical industry into a higher involvement. To count on international organizations experience to improve our conditions would be a way to speed process.</p> <p>Acknowledgement Dra. Virgina Llana, Dr. EmilioRoldan Associação Brasileira de Ataxias Hereditárias e Adquiridas, and Aliança Brasileira de Genetica.</p>
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Spanish Title:	
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