



II Congress of Rare Diseases 'Alex Garcia' celebrates success!

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February 29th is a rare date, which only happens in leap years, which is why it is the Rare Disease awareness date.

It is estimated that in Brazil around 13 million people have some rare or ultra-rare health condition. And the topic needs to be debated and clarified so that PWDs no longer suffer prejudice.

Within the proposal of Inclusion and Diversity through Information, last Thursday, February 29th, the **II Congress on Rare Diseases "Alex Garcia"** was held, bringing together speakers from all regions of the country and broadcast online to everyone.



The in-person event space, in Osasco, had maximum capacity. The online broadcast via YouTube started at 10:30 am and ended at 5:30 pm, and participants received certificates. There were more than 1500 participants from all regions of the country and also international participants from the most diverse areas such as health, law, fashion, as well as researchers, students, rare and ultra-rare patients and families, achieving the objective of Diversity and Information.

The accessible and anti-disability production, as well as the differentiated programming of Tudo Sobre Indicações Consultoria, was designed especially for the II Congress on Rare Diseases 'Alex Garcia' .

The event was attended by some authorities such as Gilberto Almazan (Ratinho), President of the Metalworkers Union of Osasco and Region and several directors, João Batista da Costa – General Secretary of the Metalworkers Union of Osasco and Region, José Elias Gois – President of the CISSOR Inter-Union Health and Safety Council of Osasco and Region, several leaders from the Trade Union of Osasco, From the Federation of Trade Workers of the State of São Paulo was Eunice Aires Camilo, advisor in the area of training and programs and Carlos Clemente President of Espaço da Cidadania. The councilors of the Osasco City Council: Batista Comunidade, Elsa Natal de Oliveira and Ralfi Rafael da Silva and the presence of Salomão Junior, Municipal Secretary for People with Disabilities and rare Osasco syndrome. Also participating were Cristiane Oliveira, counselor and second secretary of the Municipal Council for People with

Disabilities (COMPED) in the city of São Paulo, Fátima Rocha from Unidiversidades and Daniel Mendes, Relationship Manager at Brasil Eco Fashion Week and Creative Director at Âmagôh.

Highlighted with international support in the launch of Mitocon Brasil , by President Dr. Pedro Mendes and director Alexandre Braun of the Brazilian Association of Mitochondrial Genetics and Mitochondrial Diseases, being a member of the IMP – International Mito Patients (International Federation that brings together mitochondrial disease associations). It will be the first time that a Latin American country has become a member of the IMP, which puts Brazil and Latin America on the path of studies, experimental treatments and cooperation with the global community.



The program included the following actions:

The “Rare Female Entrepreneurship” axis with 2 speakers on diversity and adapted fashion; Ana Luh Garritano, Modeling teacher at Senac Lapa Faustolo and social entrepreneur Grace Santos who brought the idea of Braille and QR Code in pieces adapted for the audience to see and surprised everyone with their innovation at a congress and their respect for their role.

“Listening to Grace Santos’ lecture on “Diagnosis is not a sentence” was a life lesson” , said Glenda Felipe e Silva, blind, who is a Social Security Technician – INSS present at the Congress.

100 sunflower lanyards were distributed free of charge to those who registered, (law 14.624/23) as a symbol of identification for people with hidden disabilities. In addition to raffles for shirts without and with BRAILLE and mugs donated by Grace

Santos and other event giveaways. The SAS de LIBRAS Choir performed two songs.

The non-profit event also had a food drive for the NGO AMAMOS, which serves children and teenagers in Osasco.

Renowned “rare” speakers, including Professor Alex Garcia, one of the best-known deafblind people in the world and founder-president of the Gaúcha Association of Parents and Friends of the Deafblind and Multidisable – AGAPASM. Alex Garcia, deafblind person, with hydrocephalus and a rare health condition, who spoke about “The importance of Congress on the day of the rare and voice in authority”.

Dr Pedro Mendes Ferreira Neto spoke about “Public Policies for people with rare diseases in Brazil: from current paradigms to the necessary construction of new foundations”.

Dr. Têmis Maria Félix Geneticist brought the topic “Rare Network and patients with highly complex rare diseases”.

Dr André Naves spoke about “The Law and Rare Disease – a path to Citizen Emancipation”.

Prof. Alex Garcia talked about his inspiring trajectory “His experience in Inclusive Education and the education of deafblind people for their autonomy and independence”.



Carlos Aparício Clemente spoke about “The importance of the Quota Law and the fight for its compliance”.

And Pamela Pimentel on “Occupying spaces. the need to perceive disability as part of human diversity”.

Cristina Cagliari spoke about Ultra Rare Diseases.

Ana Luh Garritano explained “How to be Rare in the world of Fashion”.

Grace Santos spoke about “Diagnosis is not a sentence”.

For more information about the event and organization: Tudo sobre Indicações Consultoria on the website www.tudosobreinclusao.com.

To watch Congress parts 1 and 2 for free, access Diário PcD on Youtube.

Photos, click on the drive link: Photos Photographer Paulo Speranza

Credits: Paulo Speranza Congress photographer

About ICT – Everything about Inclusion Consulting

It is a Hub with a multi-diverse team called “Agents of Transformation” in actions for lectures, courses and workshops. They have a multidisciplinary nature specializing in Fashion, Sustainability, Law, Customer Service, Design/Visual Merchandising, Crafts, Event Production, Psychology, among others, with a broad and holistic approach through DEI&I – Diversity, Equity, Interaction (Inclusion) and Equality. They work in social, private and governmental organizations to create more welcoming, affectionate, healthy, equitable, accessible environments, as well as products and services that serve the entire diversity of people.

They work in line with the Brazilian Law on the Inclusion of Persons with Disabilities, Law No. 13,146, of July 6, 2015, which is a set of devices designed to ensure and promote, on equal terms with other people, the exercise of rights and fundamental freedoms for people with some disability condition, aiming at their social inclusion and citizenship.

TIC promotes events with a focus on architectural accessibility, comfortable environments and autonomy for access. They use inclusive language and empathy that take into account the representativeness, accessibility and audience interaction of audiovisual products for everyone who needs this resource: translating images into alternative words or texts and words/voice in Brazilian Sign Language for the deaf. Contact: Cristiane Mayworm. Producer and CEO. Cell phone: + 55 11 91008.7477. contato@tudosobreinclusao.com - www.tudosobreinclusao.com