

WE ARE RARE, BUT TOGETHER WE ARE STRONGER

DESMÓIDE BRASIL

ASSOCIAÇÃO BRASILEIRA DO TUMOR DESMÓIDE



DESMÓIDE BRASIL:

The Brazilian Desmoid Tumor Association - Desmoide Brasil, began its activities in 2021 with the aim of welcoming diagnosed patients. When receiving a diagnosis of a rare disease, patients often feel alone in their journey. Our goal is to show them that they are not alone and that there is a support network in Brazil.

Our mission is to foster unity, disseminate knowledge, empower, and support all members of Desmoide Brasil, so that they can take an active role in the management and care related to the diagnosis of a rare disease. We aim to ensure that all patients have access to information, research, and treatments in a safe, focused, and respectful manner.

OUR OBJECTIVES

To raise awareness among healthcare professionals	To disseminate up-to-date research
To inform patients	To maintain a patient registry
To support and empower patients	To influence stakeholders in the healthcare field

BOOKLET FOR PATIENTS OCTOBER 2022 - NEW EDITION 2024



Upon responding to the National Desmoid Tumor Registry, the patient is immediately associated to Desmoide Brasil and receives a "Welcome Booklet", prepared by Doctor Philippos Costa, Doctor Bruna Menon and Carolina Menezes. In it, the patient finds information about the DT; what it is, treatment options, and which health professionals are able to support them. With the Booklet, the patient feels welcomed and have their initial doubts resolved.

SEP / 2020

1st September Awareness lives promoted by (at that time) the Brazilian community with lives at Instagram twice a week the entire month

SEP / 2021

Desmoide Brasil promoted a series of weekly lives with national and international physicians and health professionals for the September Awareness

SEP / 2022

Held the inaugural in-person meeting in Sao Paulo, Brazil;

Officially registered the desmoid tumor awareness date in São Paulo on September 15th

JUN / 2023

Tribute from the city council of São Paulo to Georgia Garofalo as "outstanding woman" for her contribution to the rare community;

Participated of the International Patient Advocacy Group Meeting and the Global Consensus Meeting in Milan

FEB / 2021

Carol Menezes and Georgia Garofalo got together to found the Brazilian Desmoid Tumor Association

AUG / 2021

Joined "Rare Alliance", a conglomerate of groups and associations of patients with rare diseases in Brazil

AUG / 2022

Participated of the Exhibition "Rare Lives" in a subway station in São Paulo held by Rare Lives Institute

OCT / 2022

Creation of the first National Registry for Patients diagnosed with Desmoid Tumor;

Launch of the Welcome Booklet for the Brazilian Desmoid Tumor Association

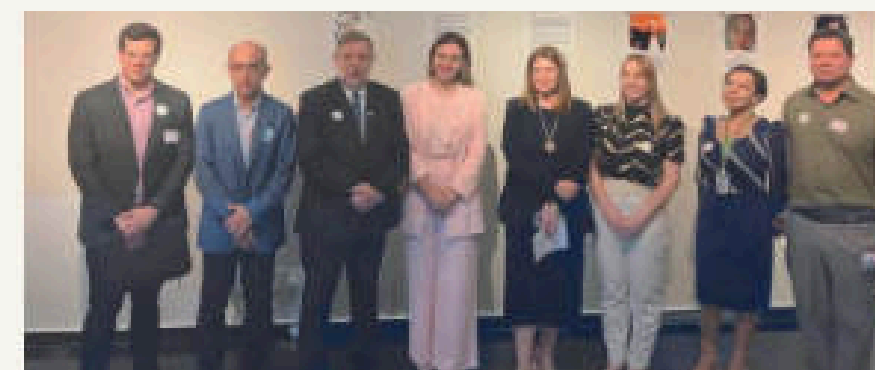
SEP / 2023

Held the II Desmoid Tumor National Symposium in São Paulo;

Light up the national congress and the Legislative Assembly of Amazonas with the color that represents the desmoid tumor;

Exhibited "Faces of Desmoid" at the National Senate.

2022, 2023 ...



"Faces of Desmoid" exhibition at the National Senate, Brasilia, from 19th to 22th of september. The Exhibition received over 3.000 people per day. Among them are politicians - senators, state and federal deputies and councilors.



As traditional for Desmoide Brasil to promote the "September Awareness" movement, on the 15th and 16th of this same month, Desmoide Brasil hosted the II Desmoid Tumor National Symposium, which brought a series of lectures on the most diverse topics within the theme of patient health in a comprehensive way - Physical and mental health.

2024 ...



International Symposium Sarcomas and Desmoid Tumor



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NOW, WE EXPAND AND EMBRACE ADVOCACY DESMOID TUMOR AND SARCOMAS



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Desmoide Brasil