

QUESTIONS?



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✦ **Become a major part of a brighter future for each and every desmoid tumor patient.**

Since its founding, the DTRF has funded a global portfolio of studies that are transforming how desmoid tumors are understood and treated. This investment has helped build critical momentum in a historically underfunded disease, advancing new insights and therapeutic approaches that were not possible just a decade ago.

Today, with promising breakthroughs on the horizon, we are at an inflection point. A continued investment in research can accelerate progress in ways that directly impact patients' lives.

RESEARCH IMPACT BY THE NUMBERS:

\$4+
million
invested in research

59
researchers
supported through
DTRF-funded grants

37
institutions driving
progress across a
global network

12
countries contributing
to collaboration and
discovery

✦ KEY RESEARCH ACCOMPLISHMENTS:

- Played a key advocacy role in advancing the first FDA-approved therapy for adults with desmoid tumors: [Ogsiveo® \(nirogacestat\)](#).
- Launched the [GODDESS© PRO](#) tool to capture the patient experience
- Published [Global Consensus Paper for Desmoid Tumor Management](#)
- Established [DTRF Patient Registry & Natural History Study](#)

✦ CURRENT RESEARCH TOPICS:

- Investigating mechanisms of spontaneous tumor regression
- Advancing targeted therapies
- Evaluating long-term outcomes and quality of life
- Strengthening global consensus guidelines for care
- Exploring innovative, less invasive treatment approaches

WHY SHOULD YOU ACCELERATE DESMOID TUMOR RESEARCH?

- Discoveries in desmoid tumor research have the potential to drive progress for other rare diseases and more common cancers.
- Rare disease progress depends on a committed network of patient advocates, researchers, and partners working together to accelerate discovery.
- For more than 20 years, the DTRF has advanced a focused research strategy that is delivering meaningful impact.
- The DTRF plays a central role in building awareness, driving collaboration, and funding research that moves the field forward.

CLICK THE BUTTONS
TO LEARN MORE.

[Watch a short message from Dr. Ben Alman.](#)

[Listen to Dr. Mrinal Gounder discuss DTRF's history.](#)

[Explore the DTRF funded grants page.](#)

[View DTRF's strategy & impact.](#)

✦ HOW CAN YOU MAKE A GIFT?

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