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# Updates Italian studies pregnancy and desmoid + other opportunities

Marianna Coppola – Manager Director Desmoid Foundation

*23 April 2021*

# WHAT WE WANT TO SHARE TODAY WITH YOU..

What does the role of the Patient Advocate  
mean to us?

How do we interpretate it  
through our Association?

How did we develop it thanks to the active collaboration  
primarily, with the surgeons and with other Patient Advocates  
around the world?



# What about the previous study on pregnancy?



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2014

## Desmoid-type fibromatosis and pregnancy: a multi-institutional analysis of recurrence and obstetric risk\*

*\*AUTHOR: Marco Fiore, Sara Coppola, Amanda J Cannell, Chiara Colombo, Monica M Bertagnolli, Suzanne George, Axel Le Cesne, Rebecca A Gladdy, Paolo G Casali, Carol J Swallow, Alessandro Gronchi, Sylvie Bonvalot, Chandrajit P Raut*

**Background:** Many women who present with desmoid-type fibromatosis (DF) have had a recent pregnancy. Long-term data about disease behavior during and after pregnancy are lacking.

**Objective:** To investigate the possible relationship between DF and pregnancy.

**Patients and methods:** Four groups were identified: diagnosis during pregnancy (A); diagnosis after delivery (B); DF clinically evident during pregnancy (C); and DF resected before pregnancy (D). Progression/regression rates, recurrence rates after resection, and obstetric outcomes were analyzed.

**Conclusions:** Pregnancy-related DF has good outcomes. Progression risk during pregnancy is high, but it can be safely managed. DF does not increase obstetric risk, and it should not be a contraindication to future pregnancy.

TOTAL WOMEN  
INVOLVED 92  
people

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# 2021 – International pregnancy and desmoid study



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## ISTITUTO DEI TUMORI DI MILANO

Dr. Gronchi, Dr. Fiore



## AZIENDA OSPEDALIERA DI PADOVA

Dr.sa Spolverato



## INSTITUT CURIE - PARIS

Dr.sa Sylvie Bonvalot



## BRIGHAM'S WOMEN HOSPITAL DANA FARBER INSTITUTE - BOSTON

Dr. Chandrajit Raut



## MOUNT SINAI HOSPITAL UNIVERSITY OF TORONTO

Dr.sa Rebecca Gladdy



## INSTITUTES

**5 different University centers & important International Hospitals** with a strong knowledge and experience about desmoid tumor

## ACTORS

It involves some of the most important specialized Doctors about desmoid, **authors of the most significant international scientific literature** about desmoid tumor

# What about the new study?



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## OBJECTIVE

The study is focused on:

- effect of pregnancy on desmoid **PROGRESSION**
- the effect of desmoid on **PREGNANCY OUTCOME**

## RECIPIENTS

- Women diagnosed with a desmoid tumor **BEFORE** pregnancy
- Women diagnosed with a desmoid tumor **DURING** pregnancy

## PATIENT ENROLLMENT

- All women eligible as patients in one of the five research centers - *Italy, Canada, USA, France*
- Internet: social (facebook, twitter, Instagram) + our website [www.desmoidfoundation.org](http://www.desmoidfoundation.org)

## DEADLINES: start and development

- Indicative starting date: **May/June 2021**
- Development: **more than 6 months** (it will depend on the number of enrolled patients)

# The ancillary study correlated to primary study

**ANCILLARY STUDY** proposals are defined as projects that involve the collection of new data directly from patients or from clinical investigators. Ancillary studies **involve the collection or derivation of data for purposes that are separate from the main trial**. The acquisition and storage of data for ancillary studies is increasingly common in the context of clinical trials.

## Objective of the ancillary study

Understand the **PSYCHOLOGICAL** well-being of women diagnosed with desmoid and would like to have children or have had children before.



It's related to the **fear** and **emotional feelings** (**QUALITY OF LIFE**) linked to the desmoid tumor experience by women who have faced a pregnancy or would like to face a pregnancy

**All women during their fertility age** with desmoid can participate to the ancillary study. Women who are no longer fertile but who were when they had desmoid can also participate.

# The role of patient advocate in the studies

A definite **quality improvement** will be the engagement of **patient advocates** who will help the development of the study: an active involvement in supporting the study has been offered from several patient advocates.

## The new role of patient advocates

In both studies (primary & ancillary) **PATIENT ADVOCATES** work with doctors and surgeons for the enrollment and data collection processes

**We are not only a BRIDGE ...  
TODAY WE ARE ACTORS IN THE STUDY**



... AND with THE **ACTIVE PARTECIPATION** OF TWO OTHERS IMPORTANT ASSOCIATIONS THAT WILL HELP & SUPPORT THE STUDY



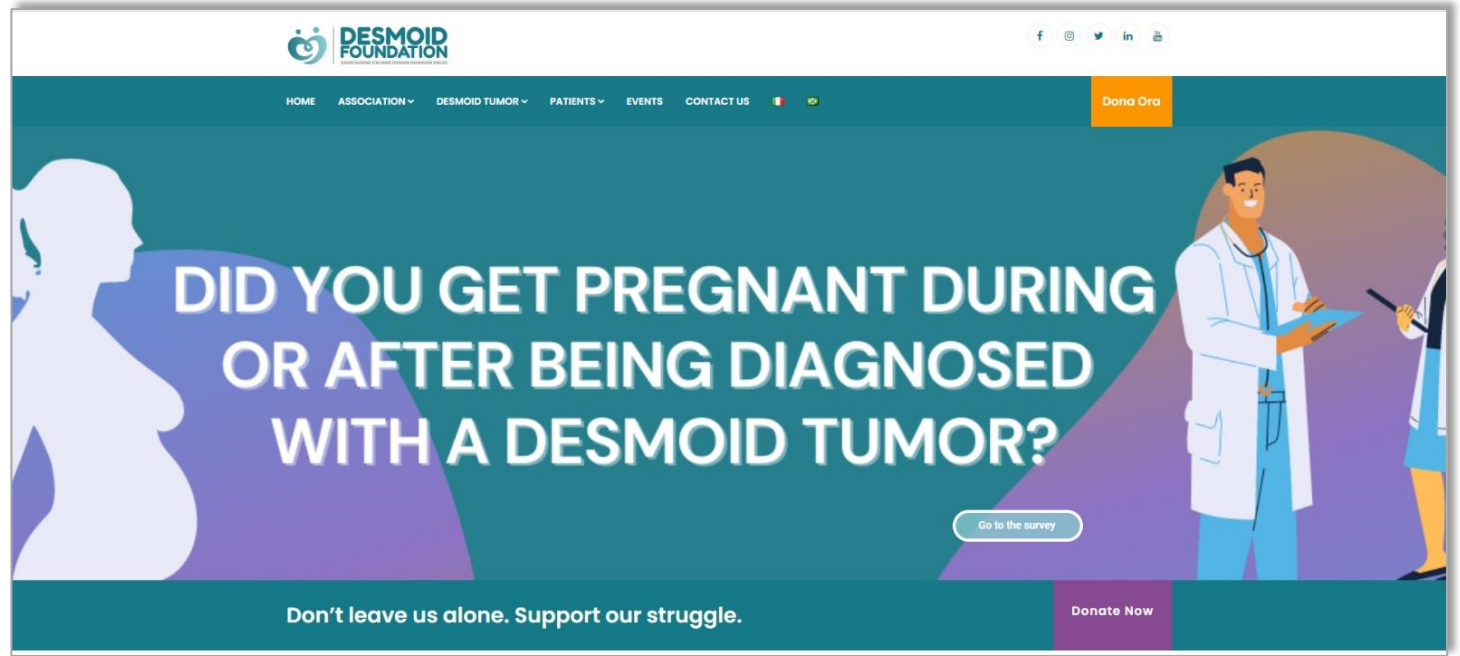
# Are you a candidate? Apply for the study!



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It could happen that you already find on internet, facebook or twitter the advertising of the study sponsor by patient association: **many patients already showed to be interested in participating!** Through the association's networks we are confident to recruit more patients!

IF YOU ARE A WOMAN WHO  
RECEIVED A DIAGNOSIS OF  
DESMOID BEFORE OR  
DURING PREGNANCY, HELP  
US AND APPLY FOR THE  
STUDY



[www.desmoidfoundation.org](http://www.desmoidfoundation.org)



# Are you a candidate for ancillary study? Apply now!

The ancillary study will consist of a few questions and will be managed entirely through the **Desmoid Foundation website: we are working on the implementation!**

**IF YOU ARE A WOMAN IN A  
FERTILITY AGE DIAGNOSED  
WITH A DESMOID TUMOR,  
HELP US AND APPLY FOR THE  
ANCILLARY STUDY**

**Write an email to this account and you will  
receive an e-mail when the study will start!**

**[2021.ancillarystudy@gmail.com](mailto:2021.ancillarystudy@gmail.com)**



# Our next project in the future



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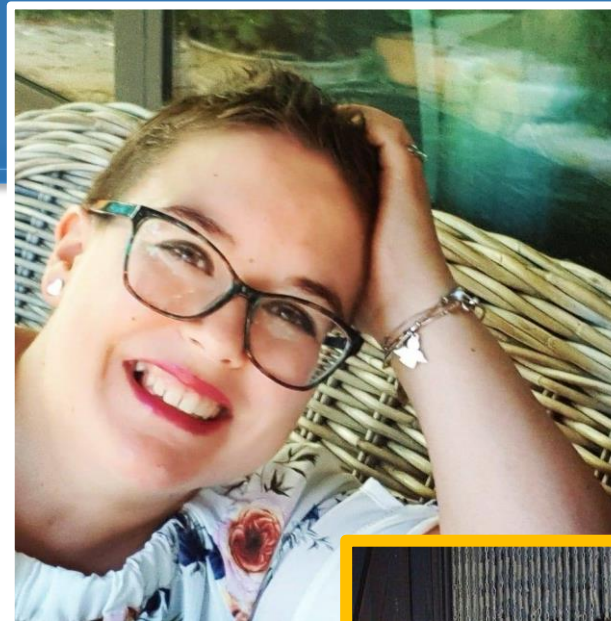
## FAP PATIENTS

Study on quality of life in **FAPs**: these patients need more attention for their particular disadvantageous situation.

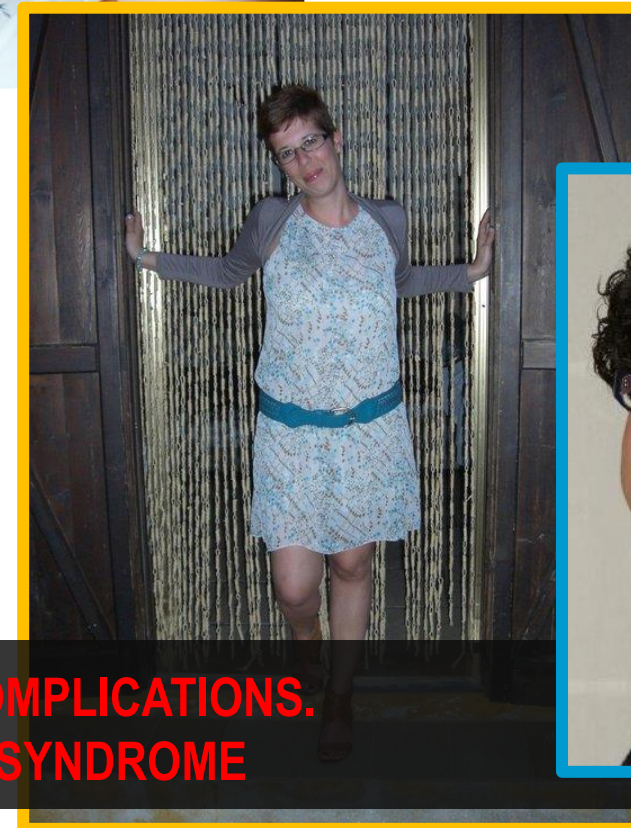
**We can do something for them.**

Together with **Dott. Marco Vitellaro - Istituto dei Tumori di Milano** we are planning a study focused on

**THEIR QUALITY OF LIFE  
&  
HOW WE CAN HELP THEM**



*Carlotta*



*Giorgia*



*Veronica*

**WE LOST YOUNG FRIENDS DUE TO INTRA-ABDOMINAL DESMOID COMPLICATIONS.  
FOR THEM TOO, WE NEED TO HELP PATIENTS WITH GARDNER'S SYNDROME**

# Our next project in the future



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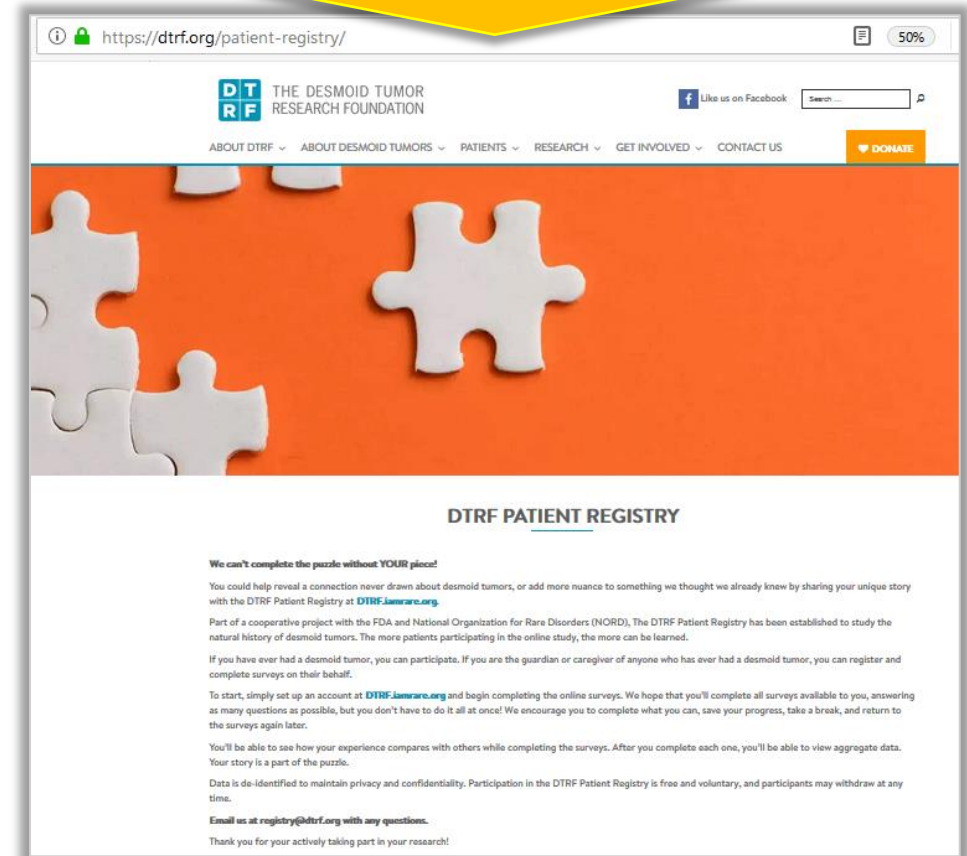
## PATIENTS REGISTER

We have about **500** members in our facebook group reserved only to desmoid patient (and familiar for patients under 18 years)

Our ambitious project is to **create a patients' registrar** where we can map all our patients

The data will be essential to understand the needs of patients, to create studies, **to help those suffering because of desmoid**

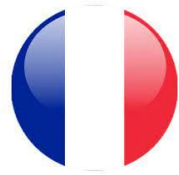
Our best practice is of course DTRF: we are learning from them



# Before we leaving, we are pleased TO THANK...



DTRF: in particular Marlene and Lynne. They are always available to help and confront us, in growing and developing new opportunities. We have a lot to learn from them



SOS DESMOID: in particular Audrey Helaine for her constant collaboration and her sincerely friendship with us



DESMOID UK: in particular Lisa Pascoe for her commitment, involvement and her support



DESMOIDE BRASIL: thanks for your energy and enthusiasm to collaborate and participate every time with us



DESMOID FOUNDATION CANADA: thanks a lot!

Before we leaving, we are pleased TO THANK...

Thank YOU SPAEN

Thank YOU Christina and all SPAEN Staff

The SPAEN Conference is a very important appointment to discussing together about desmoid. And we all need to do this.

There is no boundary to the disease, even more if it is rare... so there is no boundary to collaboration, to be stronger and fight it better.. ... **ALL TOGETHER**





**TOGETHER WE ARE  
STRONGER**

Thank You for your attention

**DESMOID FOUNDATION ITALIA**

[www.desmoidfoundation.org](http://www.desmoidfoundation.org)