

# *THE DTRF PATIENT REGISTRY*

Kelly Mercier, Ph.D



THE DESMOID TUMOR  
RESEARCH FOUNDATION

# DTRF COMMITTEE



THE DESMOID TUMOR  
RESEARCH FOUNDATION

Aimee Crago, Memorial Sloan-Kettering Cancer Center

Ellen Elkins, Patient Advocate

Sherrie Gould, Administrator of The Desmoidian

Mrinal Gounder, Memorial Sloan-Kettering Cancer Center

Lynne Hernandez, DTRF

Bernd Kasper, University of Mannheim, Germany, Universitätsmedizin

Shivaani Kummar, Stanford University

Kelly Mercier, RTI, International

Nicolas Penel, Oncologue au Centre Oscar Lambret

Raphael Pollock, The Ohio State University- The James

Marlene Portnoy, DTRF

Victor Villalobos, University of Colorado- Denver

Breelyn Wilky, Sylvester Comprehensive Cancer Center at University of Miami Miller School  
of Medicine

# WHAT IS A PATIENT REGISTRY?

- *An organized system*
- *Observational study to collect data*
- *Evaluate specified outcomes for a population defined by a particular disease, condition, or exposure*
- *Serves a predetermined scientific, clinical, or policy purpose (s).*

# WHAT IS A NATURAL HISTORY STUDY?



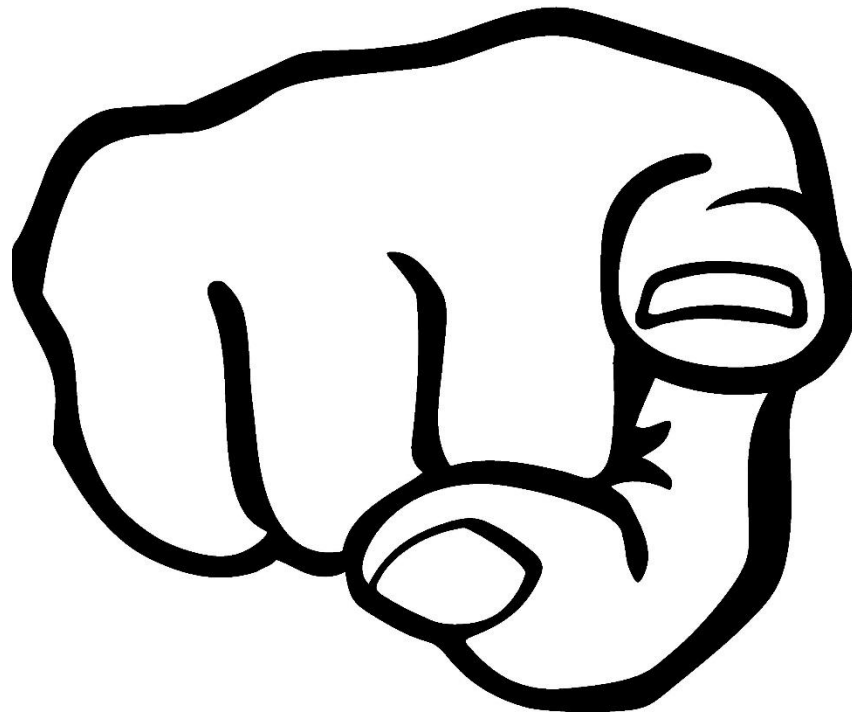
- Track the course of a disease overtime
- Identify demographic, genetic, environmental and other variables that are associated with the disease
- Define the disease population, including a description of the full range of disease manifestations and subtypes

# A STRATEGIC IMPERATIVE

*For rare or ultra-rare conditions, an international, longitudinal disease registry may be the best or only feasible way to comprehensively increase knowledge about the clinical characteristics and natural history of the disease and the long-term outcomes of treatment.*



**WE NEED YOU TO JOIN THE DTRF PATIENT  
REGISTRY AND CONTRIBUTE TO THE  
NATURAL HISTORY STUDY**



# HOW WILL YOUR DATA BE COLLECTED?

<https://dtrf.iamrare.org>

The DTRF Patient Registry [Home](#) [About](#) [News](#) [Contact](#)

[Register](#) [Log in](#)

## Log In

[Home](#) / [Log In](#)

**Username \***

**Password \***

Remember me?

[Register](#) if you don't have an account.

Forgot your password? [Click here](#) to reset your password.



THE DESMOID TUMOR  
RESEARCH FOUNDATION



# DATA ACCESS



- Critical analysis of your history by DTRF NHS committee, removing all personal health identifiers
- Critical analysis of de-identified patient history by external researchers
  - must have approval by DTRF NHS
- Patient recruitment for other research
  - must have IRB and DTRF NHS approval



# WHAT WE WANT TO KNOW

## Who are you?

- How many patients are diagnosed with desmoid tumors annually?
- Where are the tumors located? Intra-abdominal desmoids, desmoids involving the extremities, neck, etc.
- How many patients have tumors in one location compared to multiple locations?
- Does prior trauma or surgeries increase probability of desmoid tumors?
- How are patients being treated: surgery, radiation, or surgery followed by radiation?
  - What is the rate of recurrence in each of the groups?

# WHAT WE WANT TO KNOW

## How are you being treated?

- What kinds of treatments are you being prescribed, and how are they working?
- Have you have had amputations or complications requiring hospitalization?
- What type of radiation was administered, and did you have other medical problems because of this?

# WHAT WE WANT TO KNOW

## What is your daily life like?

- Do you have pain and what kind of pain?
- What is your sleep like?
- Do you have any problems getting or staying comfortable?
- Can you work or go to school?

# HOW ARE WE COLLECTING THIS INFORMATION?

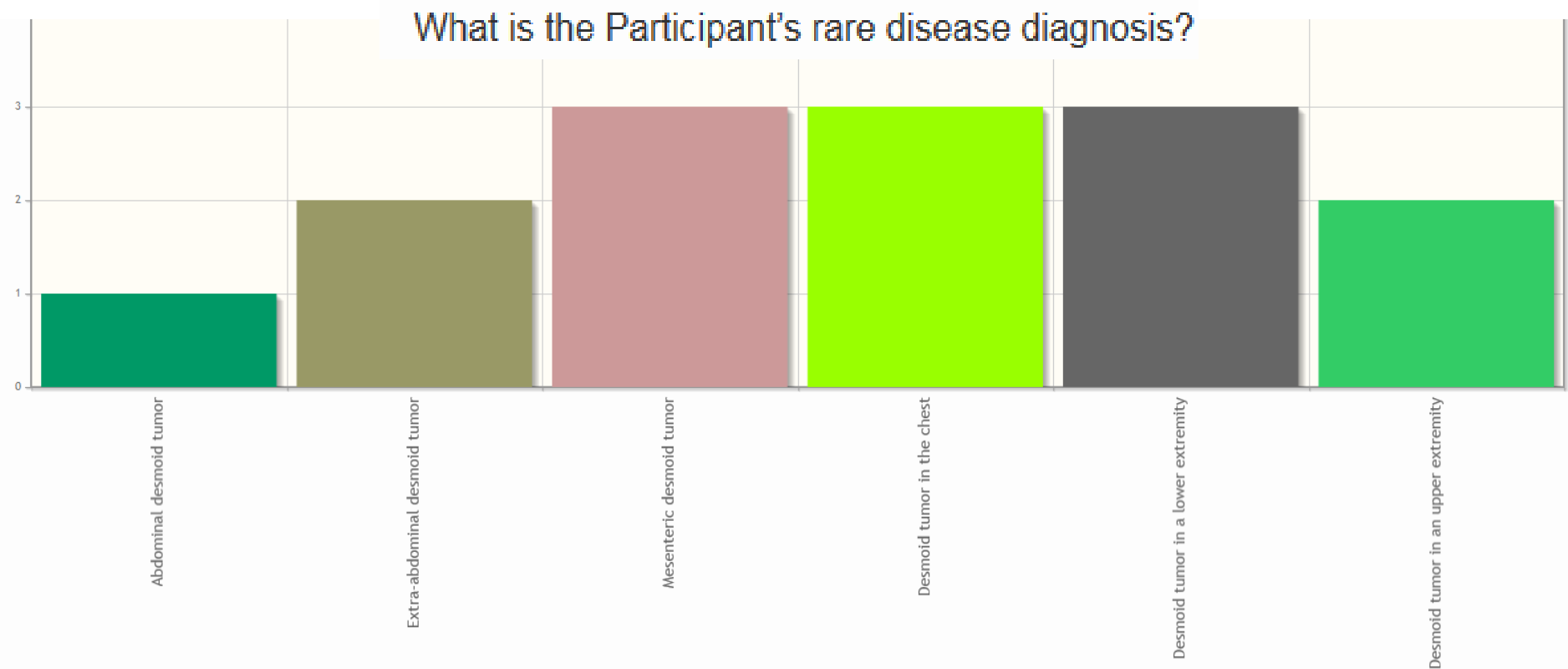
Initial Surveys (13)	Updatable (1)
<b>Surveys Not Taken</b>	
<b>Survey Title</b>	
Medical and diagnostic data	Take
Treatment and Review of Systems	Take
Quality of Life Adult Part 1	Take
Quality of Life Adult Part 2	Take
Quality of Life Pediatric	Take
Medical Data for Desmoid Tumors	Take
Diagnostic Data for Desmoid Tumors	Take
Treatment of Desmoid Tumors	Take
Desmoid Tumor Monitoring	Take
Desmoid Tumor and Pregnancy	Take
Desmoid Tumor Symptoms (PRO 1)	Take
Desmoid Tumor Symptoms (PRO 2)	Take
Desmoid Tumor and Activities	Take

Rare Diseases

Desmoid Tumors

# WHAT HAPPENS WHEN YOU COMPLETE A SURVEY?

If  $>9$  other people have participated in the survey, you will see immediately how your answers compare to others



# PROJECT STAGES

1. Project Initiation
2. Project Execution
3. Launch Registry
4. Follow Up Evaluations



[HTTPS://DTRF.IAMRARE.ORG](https://dtrf.iamrare.org)



THE DESMOID TUMOR  
RESEARCH FOUNDATION