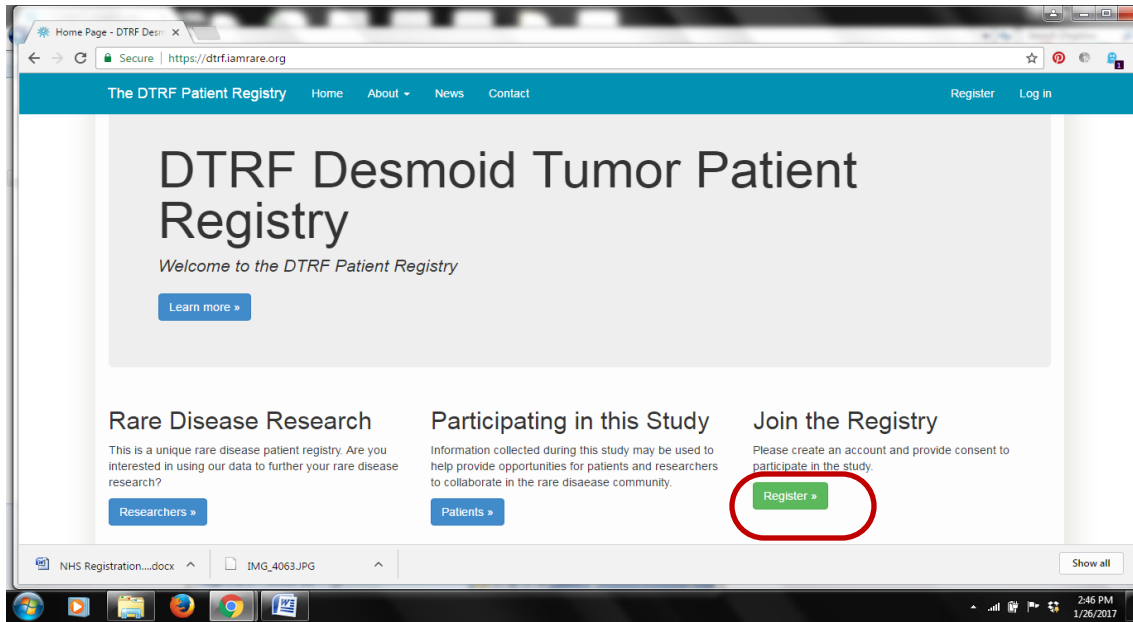


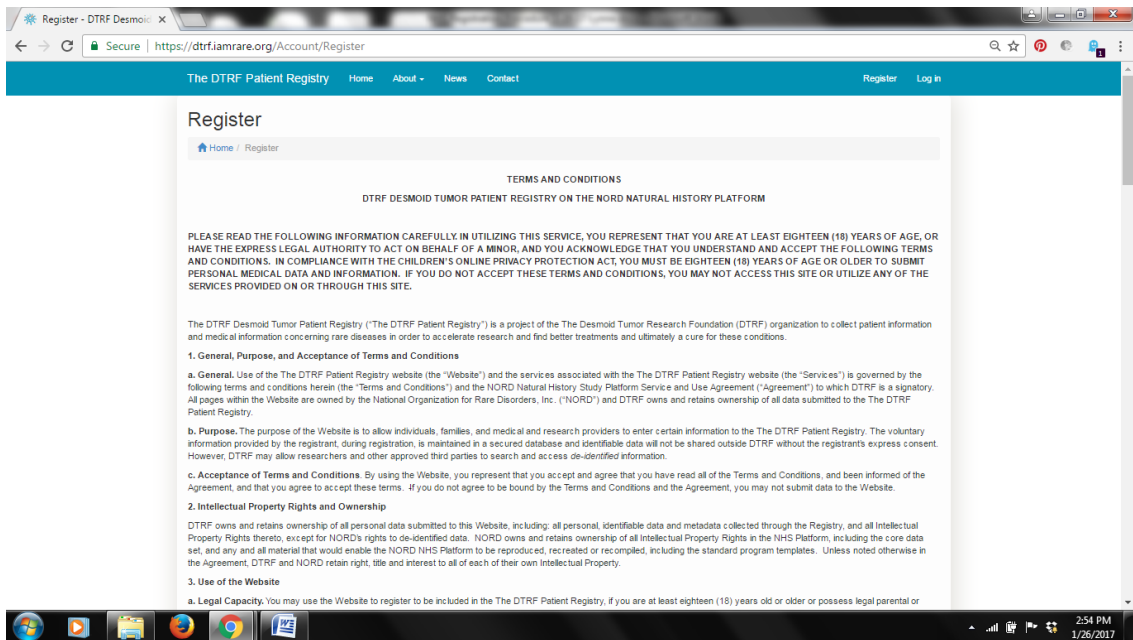
Natural History Study Registry

Procedure for Registering, Consenting and completing Surveys

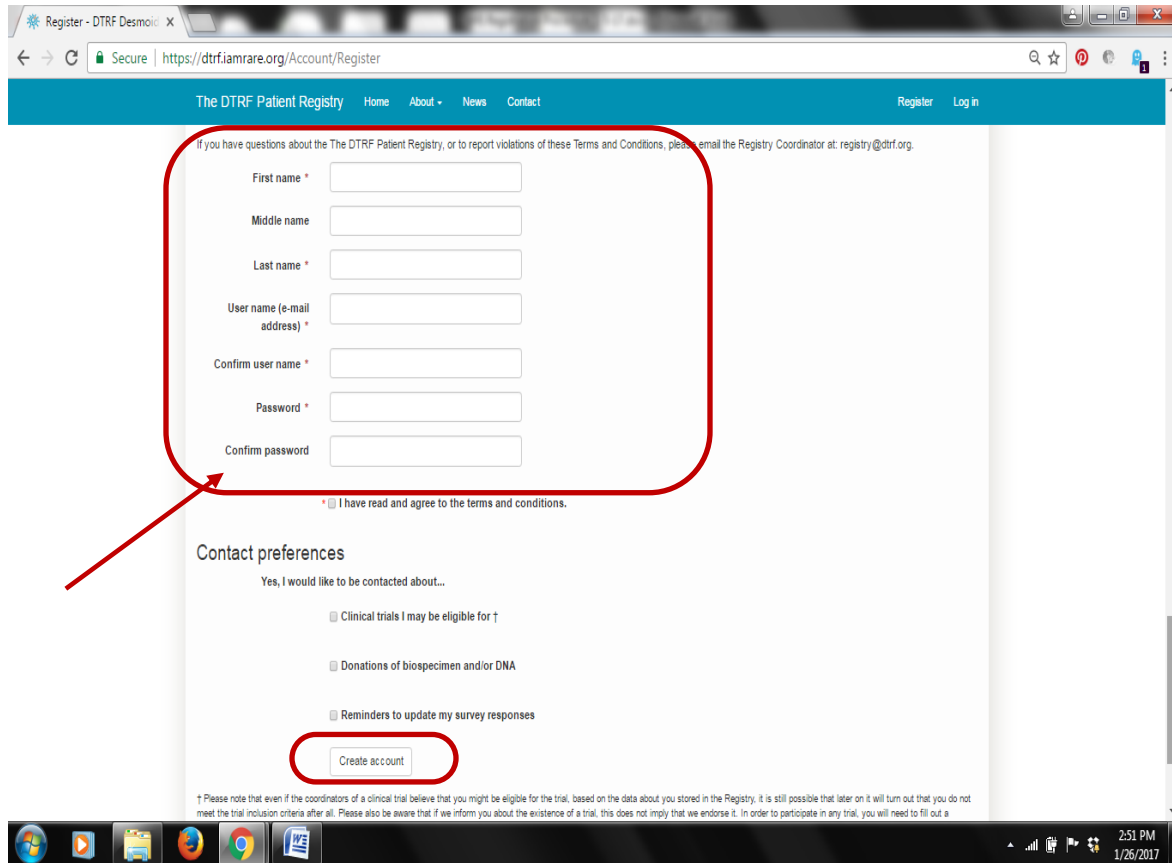
1. Go to the **DTRF Desmond Tumor Patient Registry** website at: dtrf.iamrare.org.



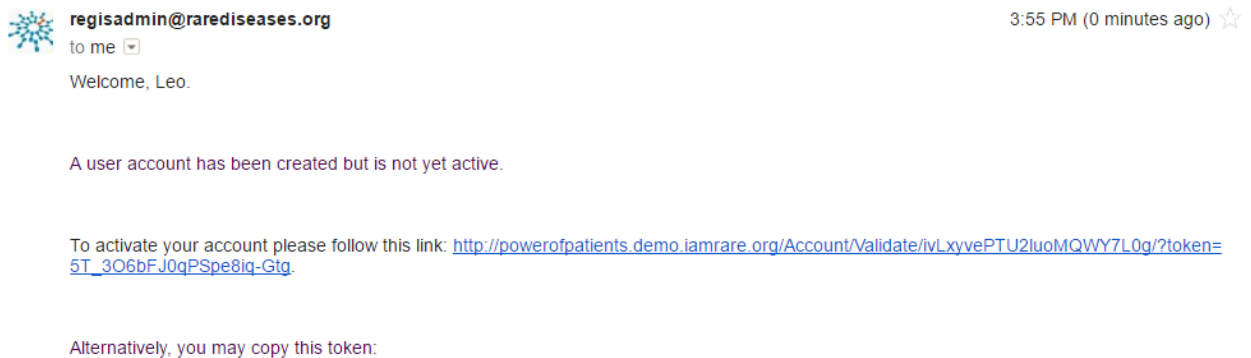
2. Click on the green **Register** button.
3. Read the **"Terms and Conditions"** document.



4. Fill in the requested information.
5. Agree to the Terms and Conditions
6. **Opt-in or out** of reasons to be contacted by study personnel
7. Click **Create Account** button



8. A confirmation email will be sent to the email address that was provided during registration. Confirm registration by copying the **Confirmation Token** from your email.



5T_306bFJ0qPSpe8iq-Gtg

9. Paste the confirmation token into the “**Confirmation Code**” field. Click **Submit**.
 - a. If the confirmation email has not been received after a few minutes, click “**Resend confirmation email**” at the bottom of the page. Be sure to check spam folders for the email confirmation.

Verify Registration

[Home](#) / [Verify Registration](#)

Thank you

A new user account has been created.

A confirmation message has been sent to srossov+1@rarediseases.org.

You must verify receipt of this email before participation in the 'The Power of Patients Registry' registry.

Activate your account by entering the confirmation code from the welcome e-mail you received. Alternatively, you may click on the link within the e-mail. Please note that using the link will require that you re-enter your user name and password.

Confirmation Code

Note:

If you do not see this email, please ensure that the provided e-mail address is correct. Please add regisadmin@rarediseases.org to your contacts so that messages from us do not get directed to your email spam.

[Resend confirmation email.](#)

[Change username/email.](#)

10. Click on “**Participant Enrollment.**”
11. Select the appropriate **Option** for granting consent.

Participant Enrollment

[Home](#) / [Participant Enrollment](#)

I would like to answer surveys for myself.

[Add yourself as a participant](#)

I am a parent, or other authorized representative, and would like to answer surveys for someone else.

[Add someone else as a participant](#)

You haven't added any survey participants yet.

12. Fill in the fields as they apply to the **Study Participant.**

Add a new survey participant

[Home](#) / [Participant Enrollment](#) / Add a new survey participant

If you are entering someone other than yourself as a participant in the registry, please ensure you are legally able to do so as the caregiver or legally authorized representative.

Your relationship to the participant *

First name *

Middle name

Last name *

Birthdate (MM/DD/YYYY) *

Can we contact the Participant or Reporter directly? Yes No

Preferred contact method

Preferred contact language

E-mail

Address line 1

Address line 2

13. Access Surveys by clicking on “Take Surveys.”

Participant Enrollment

[Home](#) / [Participant Enrollment](#)

I am a parent, or other authorized representative, and would like to answer surveys for someone else.

[Add another participant](#)

Name	Consent granted	Actions
Katie Singer	Yes	Take Surveys Edit Archive Transfer Email Consent Revoke Consent

14. Complete the **surveys** applicable to the **Study Participant**. For example, and adult would not complete the Quality of Life Pediatric survey.

- NOTE: The Reporter is listed in the top right hand corner of the page and the Study Participant is listed on the left side of the page.** If someone is answering

surveys for him or herself, both the Reporter and Study Participant fields will reflect the same name.

The screenshot shows the OP Registry website interface. At the top, there is a navigation bar with 'OP Registry', 'Home', 'About', and 'News'. Below this, the page title is 'Surveys for Melody Singer'. A breadcrumb trail reads 'Home / Participant Enrollment / Surveys for Melody Singer'. There are three tabs: 'Initial Surveys', 'Started', and 'Surveys to Retake'. The main section is titled 'Surveys Not Taken' and contains a list of survey titles: 'Medical and Diagnostic Data', 'Treatment and Review of Systems', 'Quality of Life Adult Part 1', 'Quality of Life Adult Part 2', and 'Quality of Life Pediatric'. A red arrow points to the 'Treatment and Review of Systems' title. Two callout boxes are present: one labeled 'Study Participant' pointing to the survey title, and another labeled 'Reporter' pointing to the top right corner of the page.

15. Under “**Survey Title**” click on the name of the survey to open the survey. Complete the survey. Questions marked with a red * are require a response.

The screenshot shows a survey question: "Is the Participant willing to be contacted about donating a sample of blood, tissue, or other biospecimen for research in the future? *". A red arrow points to the red asterisk. Below the question are four radio button options: Yes, No, Refused, and Don't Know. A second question is partially visible below: "Has the Participant donated a sample of blood, tissue, or other biospecimen for research in the past?". At the bottom right, there are two buttons: "Save as Draft" and "Submit as Final Response", with the latter circled in red. The footer of the survey page reads "Answering Treatment and Review of Systems for Melody Singer" and includes a "Help" icon.

16. When each Survey has been completed, click on the **Submit as Final Response** button. If not completed, Surveys can be saved as drafts by clicking the **Save as Draft** button.