



CART-WHEEL
Center for Analysis of Rare Tumors

e-Newsletter update

Thanks to your support of CART-Wheel.org, we are helping to reduce barriers to effective research into rare tumors

Update: February 2017

Scope of CART-Wheel expands

With the assistance of our technical partner BioGrid Australia, CART-Wheel has expanded to include a wider range of participants.

CART-Wheel.org now welcomes participants with:

- ▶ Any type of rare tumor
- ▶ Rare subtypes of common cancers
- ▶ Inherited rare tumor predisposition (where a gene in the family can cause tumors)

We have modified the CART-Wheel questionnaire to allow people with a genetic predisposition to cancer to register and enter their information. As many people who carry a genetic risk for cancer have not been diagnosed with a cancer, the questions have been reworded in some cases to accommodate these new participants. For example, surgery carried out to prevent cancer can now be recorded.

New psychosocial questions added

There are new psychosocial questions added to gather information on how having a diagnosis with a rare tumor or inherited rare tumor predisposition affects quality of life. These questions are designed to collect data over time so participants are encouraged to return to the questionnaire and answer those questions again in 6 or 12 months, or whenever it suits.



CART-Wheel Principal Investigator
A/Professor Clare Scott

New options for providing consent

CART-Wheel consent forms now give participants additional options:

- ▶ We can accept forms which are sent via email (either scanned or photographed). Forms can still be sent via regular mail if preferred.
- ▶ Participants can give permission to their doctor to enter and edit their data in the CART-Wheel online questionnaire. If the consent form you signed did not give you this option, consider filling out the latest version of our consent form and naming your doctor, if you think they may be interested in helping to enter your data.
- ▶ If you have participated in a research project other than CART-Wheel, you are now able to pass on the name of the project and give permission for this data to be linked to your information entered in the CART-Wheel database. See page 8 of the CART-Wheel consent form.
- ▶ Watch this space! – we are currently developing an electronic method of consent. This means that participants will be able to click a button to indicate consent to their information being used for research purposes, without having to print and physically sign a form. We hope to roll out the new method of consent early in 2017.

Revisit your questionnaire or consent details at any time

- To enter updated information on any further treatment you may have received or completed
- To complete the new psychosocial questions
- To update any of your contact information that may have changed, for example if your preferred email address changes

Keep in mind that you can change your mind about any of the options you have selected on your CART-Wheel consent form at any time. Simply fill out another consent form with your updated preferences and either post the form or email it to us at contact@cart-wheel.org. The options selected on your second consent form will over-ride your earlier form. Once the electronic mode of consent is available in 2017, you will be able to change your consent options online.

WhiMSICAL study recruiting patients with rare blood cancer

A group of Australian clinicians are working with consumer groups to conduct research into the rare blood cancer Waldenström's Macroglobulinemia (WM). The group is using data entered by patients in the CART-Wheel questionnaire to investigate issues such as patient demographics, disease staging and progression, treatments and their side-effects. Aided by the efforts of WMozzies, the Australian patient support group for WM, and its Leader Andrew Warden, the group has already presented data at both national and international meetings. Andrew is also a Co-investigator of WhiMSICAL. There are plans to increase the number of Australian participants to 100 and continue to provide the medical community with a better real-world understanding of this disease.



WhiMSICAL Principal Investigators Dr Ibrahim Tohidi-Esfahani and A/Prof Judith Trotman and Co-investigator Andrew Warden

Your CART-Wheel information in a summary

If you would like to keep a record of the information you have entered into the online questionnaire, remember that you are able to print a summary. Or, if you prefer, you can save the summary to your computer as a pdf file. You might like to share your summary with your doctor for their own records, or to review for completeness of data.

Have you forgotten your CART-Wheel password?

If you have lost track of your CART-Wheel account password, you can be sent a new password. Go to www.cart-wheel.org and click on "Sign in" at the top of the page. This will take you to the login page. Then click on "Forgot your password?" You will be asked to enter either your username or the email address you used when you registered, along with your full name.

A new random password will be emailed to you. You will probably want to change this password to something you find easier to remember once you login to your account. Make sure you write down your new password in a safe spot. Contact us if you have any problems: contact@cart-wheel.org

Over 300 people are now consented to CART-Wheel

We now have over 300 people who have registered with CART-Wheel and given consent for their information to be used for research purposes. We welcome new registrations so let your friends, family and doctors know about this important project and keep CART-Wheel in motion! If you are involved with a rare cancer support group, please share our website and encourage others in your community to register with CART-Wheel. Thanks to all our participants for helping to drive research into rare cancers.

Contact us

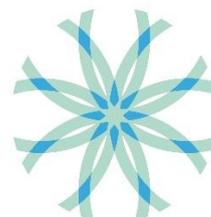
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