



CART-WHEEL
Center for Analysis of Rare Tumors

WhiMSICAL Study



Waldenström's Macroglobulinemia Study Involving CART-WHEEL

**a world-first, ethically-approved, comprehensive survey
of patient-derived data about their WM experience**

What is WhiMSICAL?

WhiMSICAL is a global clinical trial inviting Waldenström's Macroglobulinemia (WM) patients to provide their clinical data, which will help advance current knowledge and understanding of this disease. CART-WHEEL (Center for Analysis of Rare Tumors) is a database designed to address some of the barriers facing effective research into rare cancers.

How does it work?

CART-WHEEL uses a privacy-protected, internet-based questionnaire. WM patients complete this questionnaire on the CART-WHEEL.org website and have control over personal details by providing consent to different uses of entered data. The questions cover areas including:

- Patient demographics
- Disease specifics: staging, chronology of symptoms, IgM levels, full blood count information, Somatic MYD88 and CXCR4 mutation status, etc.
- Treatments, how they were accessed, and treatment side-effects
- Personal and family medical history

Gathered information is stored securely and treated confidentially. It is analysed by WhiMSICAL and CART-WHEEL researchers only, to gain a better understanding of WM.

Participants can print out a summary of the questions and responses (their profile) for their records and/or review with their specialist. Profiles can be updated at any time and patients are encouraged to do this regularly, e.g. every 6 months.

How Can I take Part?

If you would like to take part, please visit the CART-WHEEL website (www.cart-wheel.org) to register. Once logged in, you can consent to participate online ("My consent details") and enter your information. Alternatively, you can consent by printing and emailing or posting the signed consent form to CART-WHEEL. Your data cannot be utilised for research until your consent has been given.

THANK YOU FOR YOUR INVALUABLE HELP!!

If you have any queries about the WhiMSICAL Study, please contact:
A/Prof Judith Trotman, Dr Ibrahim Tohidi-Esfahani (Principal Investigators)
Concord Repatriation General Hospital, Concord, NSW, 2139, Australia
Phone: +61 2 9767 7243

Alternatively, queries can be emailed to WhiMSICAL@IWMF.com