



Waldenström's Macroglobulinemia Study Involving CART-WHEEL

WhiMSICAL

STUDY NEWSLETTER #2

WhiMSICAL database: empowering patients internationally to contribute patient-derived data for observational research

KEY POINTS

WhiMSICAL, research run by doctors and WM patients FOR WM patients

WhiMSICAL is already advancing WM research with presentation at ASH, the world's premier haematology conference

Please regularly update your data. Print out your CART-Wheel.org Summary and review with your doctor

WhiMSICAL is at 296 patient researchers, 30% of its goal "Project 1000" to achieve Big Data, so every WMer counts!

Pay it forward

IWMF President Carl Harrison has driven the international rollout of WhiMSICAL with the key message of "Pay it forward". He has called on WM patients to join the WhiMSICAL database to help inform themselves and WM researchers across the globe as we advance towards a cure for current and future WM patients around the world. Joining benefits all WMers and is a personal scientific contribution to conquering WM. WhiMSICAL is the only database that collects patient data from around the world in one centralized location. Every single patient matters as their

joining moves us forward towards "big data" collection for Waldenström's Macroglobulinemia on behalf of patients, caregivers, scientists, researchers, and clinicians around the world! Big data will help to identify new disease patterns and real-world outcomes that will drive WM research forward. Consider it your opportunity to personally advance research into eradicating WM.



Carl Harrington (IWMF President), Dr Ibrahim Tohidi-Esfahani, and Dr. Judith Trotman (at ASH 2017 Poster Session)

What can you do?

1. **Take part!** Every single person counts. Ensure your online **consent form** is completed ("My Consent Details" tab top right)



CART-WHEEL
Center for Analysis of Rare Tumors



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of log in page) as your data cannot be used otherwise

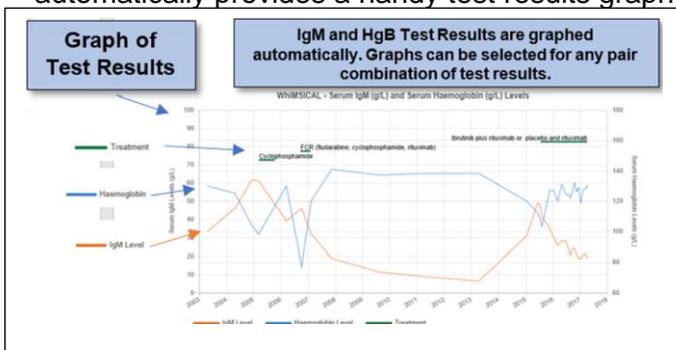
2. Spread the word, to your WM doctor and community.
3. Regularly (six monthly) return to CART-Wheel.org and update your data to maximize its value for WM research. Currently approximately 60% of questions have incomplete answers
4. When responding to the questions on symptoms and pathology results, focus on entries at diagnosis, before and after each treatment first
5. If you are having any difficulties with the questionnaire, contact us at whimsical@iwmf.com

Patient's voice and experience

The European Consortium for Waldenström's Macroglobulinemia has proposed WhiMSICAL for WM patients to use as a platform for recording the patient's experience. *"We urge WM patients globally to contribute the patient voice, your experience, to WhiMSICAL"*. Professor Buske, ECWM Coordinator, said WhiMSICAL *"data provides the patient voice so instrumental in informing and driving medical research to focus on the priorities of patients"*.

Tool for every WM patient

WM patients can consider WhiMSICAL to be their living document, to increase their health literacy and engage them in their healthcare. WhiMSICAL automatically provides a handy test results graph



Active participation in their own data collection and ongoing input empowers WM patients and encourages prioritisation of their health. WhiMSICAL assists networking for patients who often feel isolated and influences community culture to better engage in health developments. The WhiMSICAL summary of their medical story at the end of the questionnaire facilitates discussions with healthcare professionals in reviewing disease history, monitoring progress and considering treatment options.

WhiMSICAL database presentation at ASH

The WhiMSICAL database was presented in December at the American Society of Hematology (ASH) annual meeting in Atlanta, with over 20,000 haematologists and researchers attending.

A full-size version of the WhiMSICAL ASH poster is provided at <http://www.wmozzies.com.au/index.php/whimsical>

The ASH poster demonstrated the feasibility of the WhiMSICAL database as a patient-derived data registry. Highlights from the WhiMSICAL database include:

- The 279 participants were predominantly from the USA (45%) and Australia (23%)
- Median age at participation was 67 years (up to 85 years!) and at diagnosis 60 years



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- Fatigue was the most common symptom at diagnosis (44%)
- From diagnosis to first treatment, median time was 82 days. Median for USA patients was 48 days and Rest of World was 122 days.
- Forty different first-line treatment combinations were entered by 173 patients
- Most patients had only one line of therapy (47%) or were untreated (24%)

None of the research would have been possible without the 279 WM patients who have contributed their de-identified data, tumour/bone marrow details and gene testing, reports from clinicians, treatments, side-effects and other psychosocial and family history information via the CART-Wheel.org database. The research community owes them a debt of gratitude for the time and effort that went into taking part.

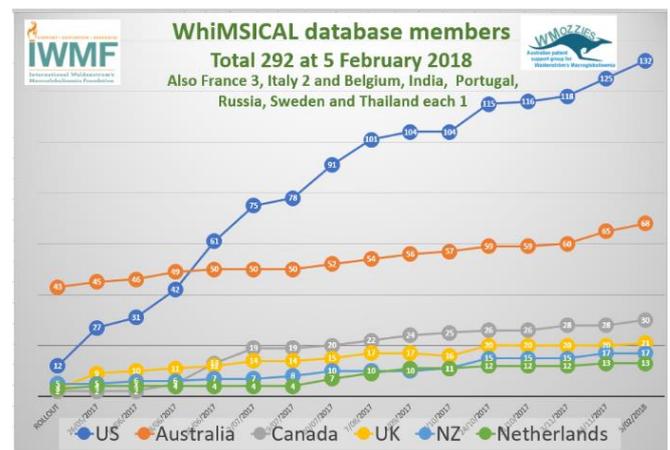
What next?

To demonstrate the value of patient-derived data to the research community, a validation exercise is in progress comparing the accuracy of patient entered details against clinical records. In 2018, an addition to the database is also planned to have WhiMSICAL participants provide ongoing Quality of Life (QOL) data. QOL measures are needed for guiding clinical trials, registries, clinical practice, and more recently, drug approval.



WhiMSICAL recruitment is at 30% of goal

The WhiMSICAL Database was launched in Australia in June 2016. The local recruitment drive demonstrated initial project feasibility with 69 participants. Following international promotion in May 2017, this increased to 296 participants from 14 countries. This is 30% of the “big data” goal of 1,000 members.



“Pay it forward and add your voice to WhiMSICAL”

Quick Links

Further details about WhiMSICAL database are at

www.wmozzies.com.au/index.php/whimsical/

www.wmozzies.com.au/index.php/whimsical/whimsical-frequently-asked-questions/

Support from WM patients using WhiMSICAL
whimsical@iwmf.com

Technical support and user problems:
WhiMSICAL CART-WHEEL:
contact@cart-wheel.org

