

A•NZ MEMBERSHIP

WMOZZIES MEMBERSHIP

Patients & associates	174
Physicians & Medical	34
Total	208
Proportion of WM Australian population est.	20%
WM New Zealand membership	34

WMOZZIES USAGE

IWMF Torch Quarterly	87%
WMozzies Talk-List (3 postings per week)	47%
WhiMSICAL database	42%
Facebook, WM Network, Leukaemia Foundation	19%
IWMF Connect (dozens of posts daily)	15%

A•NZ PATIENT LOCATION - %



is on YouTube.

www.youtube.com/watch?v=a9PoV8Jbj7c

ClinTrial Refer smart-phone and iPad/Tablet tool provides clinicians, research staff and patients with instant knowledge of currently recruiting trials. The app. was awarded a \$50,000 prize in a US worldwide US Competition for Clinical Trial Innovation.

WMozzies at patient advocate HealtheVoices event

WMozzies leader Andrew Warden was with dozens of patient advocates for the HealtheVoices conference sponsored by Janssen in November. The event for health advocates was about the power of health advocacy online. It included a range of panel discussions featuring patients, advocates and other experts. The panels had a significant focus on online patient advocacy, the development of content, and the use of different platforms. Topics covered:

- Panel on Helping, healing and the risk of hurting discussing how the internet has changed the way patients connect and interact with each other
- Patient with a rare condition telling about her patient advocacy leading to wider recognition as an expert voice.
- Health advocate dealing with the challenges of emotional health in online advocacy - How people can balance the benefits of connecting and advocating online while dealing with negative interactions and maintaining boundaries.
- Communications expert on content generation and expanding the reach of advocacy.
- Comedian and patient on whether it is okay to make jokes about your own chronic illness. He talked about his own considerations when using humour to talk about what can be traumatic patient experiences.

WMozzies survivor tells his story to Australian Government

Having given his Story of Hope to IWMF in 2015, September 2018 WMozzies survivor, Michael van Ewijk, was invited with Prof Judith Trotman to Parliament House Canberra to tell his story to the Australian Government Minister of Health the Hon. Greg Hunt Member, House of Representatives. In 2014 Michael was the first patient in Australia to have Ibrutinib. He was in the iNNOVATE clinical trial at Concord Hospital in Sydney under the care of Prof Judith Trotman. Michael told the Minister of Health about the truly amazing results from the Ibrutinib treatment and also about the ClinTrial Refer App. The app. enabled him to locate and join the trial. His story



Michael van Ewijk Prof Judith Trotman Hon. Greg Hunt MHR



WMozzies patient story presented at Cancer Institute NSW Innovations Conference

WhiMSICAL Patient Investigator's personal cont.

experience was featured in presentation on WhiMSICAL at the Conference in Sydney by WMOzzies Leader Andrew Warden. His personal patient story highlighted the need for WM Patients' de-identified data to be shared "Eleven years ago, my treatment resulted in multiple emergency hospitalisations with a week-long stay in an isolation ward. Of my WM friends who had this same treatment one subsequently died and one nearly died. None of us were in a clinical trial so our patient experience was not shared widely.

Our patient story remained in one hospital's records. Each of our records was in a virtual silo. Our de-identified experience was not available for research for the benefit of doctors in other hospitals. - The WhiMSICAL database is to overcome this major shortcoming."

A•NZ Torch Future Issues

Contributions of topic ideas and articles for the next edition are welcome. Please send to:

- mvep@tpg.com.au Australia
- lea.hullett@gmail.com NZ

Suggestions already received include:

- Availability of funding in Australia and NZ for WM treatments,
- Names of haematologists and treatment centres with expertise in treating WM,
- News on new treatments in Australia and NZ such as ibrutinib, Zanubrutinib and Venetoclax



WHIMSICAL STUDY GRAPHS

These graphs taken from the Whimsical Study database illustrate the progress of Andrew Warden (top graph) and Michael van Ewijk (lower graph) on the iNNOVATE clinical trial at Concord hospital under Prof. Judith Trotman.

Michael was in the C arm and received Ibrutinib alone. Andrew was in the double blind arm and received the placebo and Rituximab.

