

## The Myeloma and Related Diseases Registry

December 2015 Newsletter

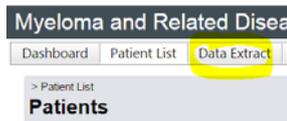
### Welcome to the December 2015 MRDR newsletter!

2015 has seen an impressive increase in recruitment, with over 330 patients registered since the beginning of the year. We currently have over 850 patients in the registry.

**Can we make it to 1000 over the Christmas break?  
Please keep up the excellent efforts that have seen recruitment increase in record numbers this year!  
Sincere thanks to all sites for your hard work; we really appreciate your support of the registry.**

### Database upgrades

Sites now have the ability to access their own data using the 'Data Extract' button on the registry. This enables sites to check the completeness and quality of their data, and to monitor and evaluate their own practice. Minor changes have also been made to other areas including the '24 hour total protein' and '24 hour BJ protein' fields under 'Diagnosis'. A meeting with data managers is set for 2pm on Thursday, December 3 to identify and prioritise any issues people are having with the database and potential solutions/changes required.



### MRDR at the HAA conference

The MRDR team attended the combined Scientific Meeting of the National Societies for Haematology, Blood Transfusion and Thrombosis (HAA) in October 2015. Professor Andrew Spencer, Associate Professor Erica Wood and Dr Elizabeth Moore hosted an interest group meeting during the conference. Andrew Spencer provided an update on the MRDR and the Myeloma 1000 Project and presented initial results from the registry and recent findings from myeloma DNA studies. He emphasised the importance of the registry as a source of data for research and encouraged the development of potential projects. The meeting was well attended, with over fifty people joining the breakfast to hear about the MRDR.



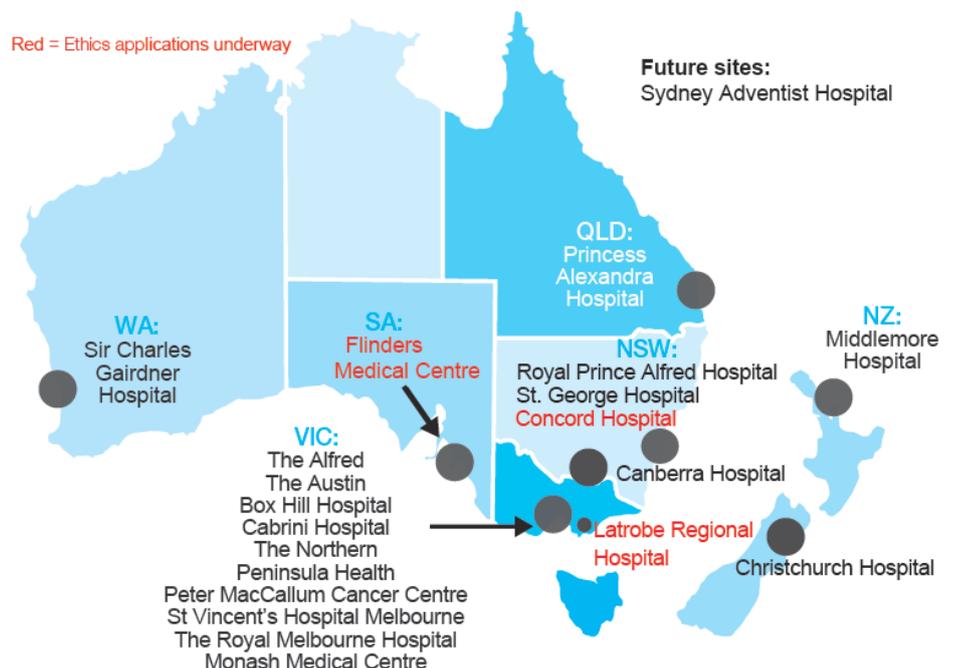
Professor Andrew Spencer presents at the MRDR Interest Group Breakfast.

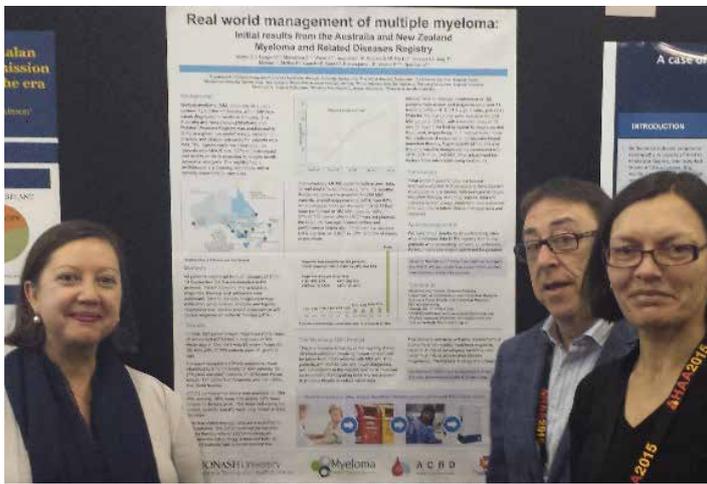
### New and future sites

Welcome aboard to sites that commenced recruitment in 2015: Box Hill, Canberra, Christchurch and Cabrini Hospitals, and Peter MacCallum Cancer Centre have all 'launched'. We now have 17 sites with ethics approval and 3 more with applications underway (see map).

Right: MRDR sites

Novartis, Celgene and Takeda Corp support the MRDR and enable this important research to continue.





Erica Wood, Andrew Spencer and Liz Moore with the MRDR poster at HAA.

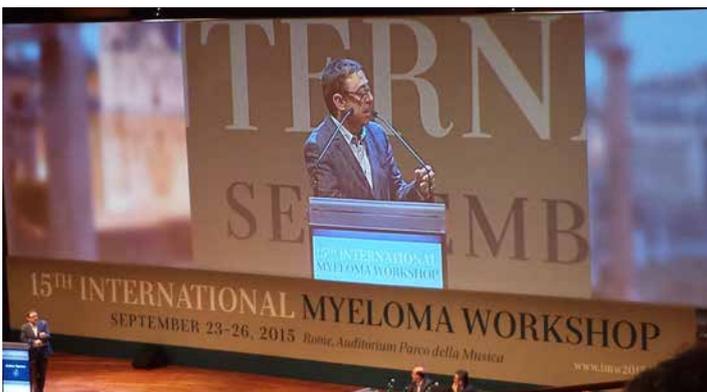
The MRDR poster was presented at HAA detailing initial results from the registry.

### MRDR attends the 15<sup>th</sup> International Myeloma Workshop in Rome

The MRDR forged valuable links with sister registries at the International Myeloma Workshop (IMW) in Rome in September 2015. At this biannual workshop attended by over 1500 delegates, members of the MRDR Steering Committee and Liz Moore met with representatives of the Austrian, Canadian and Korean Myeloma Registries. All registry teams expressed interest in a proposed international research collaboration. Initial MRDR results were presented in a poster at IMW and the registry was represented at the Asia Myeloma Network meeting. In addition, Professor Andrew Spencer delivered three invited presentations at the IMW.



MRDR team meet with representatives of the Austrian and Korean registries.



Andrew Spencer presenting at the IMW.

### Myeloma 1000 Project update

The Alfred and St Vincent's Hospitals in Melbourne are recruiting steadily to the Myeloma 1000 Project; a biobank sub-project of the MRDR. Congratulations to Box Hill Hospital which has just commenced recruitment to the substudy and Frankston Hospital will start soon. The Myeloma 1000 project has initially rolled out to Victorian sites to test systems for specimen delivery and receipt, and will soon commence interstate. We now have 40 patients participating in the substudy.

The Myeloma 1000 Project is supported by Amgen Australia, Janssen-Cilag and Bristol Myers-Squibb.

### MRDR PhD Student – Welcome Krystal Bergin

We now have a PhD student working with the registry. Krystal Bergin is a Haematology registrar at the Alfred Hospital in Melbourne who specialises in Myeloma. Her doctoral thesis will be partly based on information from the MRDR with some planned publications. Krystal has recently worked as a haematology registrar at the Peter MacCallum Cancer Centre and prior to that as Bone Marrow Transplant Fellow in Vancouver in 2012. She has presented her previous research at National and International Haematology meetings and is keen to work with us. In her spare time Krystal enjoys reading and travel.



### New research projects

The MRDR was designed to support and encourage research. If your team has an idea for a research project using MRDR data, we encourage you to email us with a proposal. Steering committee members will provide feedback prior to final approval.

### Participate in the MRDR website

There is now a News section on the MRDR website (<http://mrdr.net.au>) and we would like to include photos of MRDR site teams. If you have a photo for us, please send it in.

### Season's Greetings!

As 2015 comes to a close, we thank you for your contributions! We would not have come this far without your expertise, skills, interest or support. We look forward to working with you in the coming year and wish you a very happy and safe holiday season.



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