6 May 2021

Minister Greg Hunt

PO Box 6022  
Parliament House  
Canberra ACT 2600

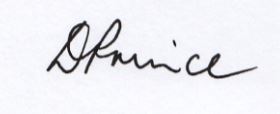
Dear Minister Hunt

Request for funding

Haemochromatosis Australia

Please find attached a request for funding to develop a national cloud-based patient registry. Building on our history of successful delivery of projects funded by the Department of Health under the Chronic Disease Prevention Policy, Haemochromatosis Australia is requesting further funding under a three-year agreement to establish, manage and promote a national cloud-based patient registry. A registry will enable routine collection of patient health information, for the purpose of informing and supporting research into haemochromatosis and innovations in treatment, in order to prevent chronic conditions resulting from iron overload disorder.

Thanks for considering the attached proposal.



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Pre-Budget Submission for funding for 2021 - 2024

Haemochromatosis Australia

Request for funding

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National Patient Registry

Haemochromatosis Australia is seeking funding to develop a cloud-based patient registry in [REDCap](https://projectredcap.org/about), establishing a national resource for clinicians and health researchers now and into the future. Outcomes of a cloud-based patient registry would support research into the role of iron in a number of related chronic health conditions including liver disease, arthritis, diabetes and heart conditions, as well as supporting opportunities for future research into the impact of iron on the brain.

No Australian patient registry currently exists to support the advancement of research into iron related disorders and the development of innovative therapies to treat haemochromatosis. Individual clinicians in different specialty areas (rheumatologists, gastroenterologists, hepatologists, cardiologists and endocrinologists) maintain patient information in their own systems and may contribute data to other registries such as the Australian Rheumatology Association Database or the Australian Genetic Heart Disease Registry, the Australian Orthopaedic Association National Joint Replacement Registry, GenomeConnect: the ClinGen Patient Registry (international). However, there is no national registry, enabling the collection of patient information *across* the specialty areas that deal with outcomes of haemochromatosis.

A legacy database, established by gastroenterologist Professor Lawrie Powell at the Royal Brisbane and Women’s Hospital in over 30 – 40 years of clinical practice, holds data for over 4,000 patients and includes serum and tissue samples. Professor Powell’s database is currently housed at QIMR Berghofer Medical Research Institute in Brisbane. Although data held there are still being used by local, national and international researchers, there is a high risk of losing a strong heritage of Australian (and international) research into the impact of iron on liver disease because of the manual nature of accessing the data. Furthermore, no new data are being added because of Professor Powell’s retirement.

While there is greater awareness of Haemochromatosis there is a need for better understanding of the impacts of iron on chronic conditions, and of new therapeutic options. The current treatment for iron overload disorders is phlebotomy (i.e. blood donation), which is not always suitable for all patients. New treatments are being investigated and trialed but there is no national patient registry to facilitate the research process.

A national cloud-based registry will enable Australian research into iron-related disorders and their treatments, in order to prevent chronic conditions arising from iron disorders.

Haemochromatosis Australia aims to build on the now increasing health practitioner and public awareness of haemochromatosis to promote the registry and its benefits – to patients, practitioners and the research community. The previous projects aimed at raising awareness among young adults and providing health practitioner education provide a springboard for a national patient registry. Updating the online learning program for general practitioners and extending it for a third year will support the dissemination of information about the national patient registry.

Strong connections of the principal collaborators will facilitate engagement within the medical and research communities. Haemochromatosis Australia’s relationships with Lifeblood, Primary Health Networks, other patient groups and organisations will support the engagement of doctors and patients.

The uptake of access to data by Australian and international researchers will prove the value of a national patient registry. An Australian patient registry may provide a model or platform for groups in other countries, thereby increasing opportunities for research and collaboration internationally with further benefits for Australian and international patients with haemochromatosis.

Project objectives

1. To scope and build a patient registry based on collaborative design principles, through consultation with health practitioners, researchers and other patient registry owners in Australia and internationally.
2. To facilitate and enable data integration from Professor Powell’s legacy database (approximately 4,000 patients), and potentially Lifeblood’s Therapeutic Donors (currently approximately 10,000 patients).
3. To establish protocols for data quality, integrity, security, addition and data access.
4. To develop communication plan and promotional materials and activities to encourage patient participation and participation of medical practitioners.
5. To update the current online learning program to include information about new patient registry and extend its availability for a third year.

Funding request $614,000 (incl GST) over three years

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| Registry developer | $30,000 |
| Data cleansing QIMR dataset for migration to new national registry | $20,000 |
| Collaborative design meetings expenses (travel/accommodation) SYD/Perth/Brisbane | $40,000 |
| Project management over 3 years | $144,000 |
| Costs to publish open access in relevant research journals | $20,000 |
| Promotion at relevant health conferences 2022 – 2023 | $100,000 |
| Advertising costs including assets for publication online and in relevant journals & magazines | $100,000 |
| Protocol writing and publication | $50,000 |
| Cloud hosting services for 2 years | $50,000 |
| Online accredited learning program extended for one year | $60,000 |

Deliverables

* Dataset for the registry identified and published through consultation with clinical researchers and project collaborators.
* Prototype built and populated with legacy data from Professor Powell’s QIMR database.
* Plan for sustainability of registry developed.
* Ethics approval received for data collection
* Protocols for adding and accessing data tested, amended and refined if necessary and published.
* Data integrity and security reviewed, tested and updated if necessary.
* Funding for ongoing maintenance and sustainability sourced.  
  Data from 4,000 patients loaded to registry, validated and tested.
* Plan and materials for promotion of registry developed.
* Data from an additional 1,000 patients loaded to registry, validated and tested.
* Registry transferred to cloud ready for launch.
* Agreement from minimum of 10 relevant patient organisations and other collaborators to communicate registry from January 2024 via website links and social media.
* Communication plan to promote the registry nationally (and internationally) within medical and research communities launched.
* Promotion of the registry within the national and international medical and research communities via the Australian Society for Medical Research, the Gastroenterology Society of Australia (GESA), the Australian Rheumatology Association, the Liver Foundation, Royal College of Pathologists Australasia, The Haematology Society of Australia and New Zealand, The European Alliance of Associations for Rheumatology and to GPs via the primary health networks, RACGP, ACRRM, and other professional and research associations.
* Promotion of the registry to patients via Haemochromatosis Australia, the Consumer Health Forum, Arthritis Australia, Diabetes Australia, and international patient alliances such as Haemochromatosis International.
* Data from 5000 patients available for use and accessed by researchers.
* Online learning program updated to include information on registry

Principal collaborators

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| Collaborating partners | Activity | Affiliations |
| Haemochromatosis Australia | Project management | Consumer Health Forum, Arthritis Australia, Diabetes Australia, The Heart Foundation, Haemochromatosis International |
| Professor Grant A. Ramm, Head of Department Cell and Molecular Biology;  Group Leader Hepatic Fibrosis  QIMR Berghofer Medical Research Institute  2020 recipient of Distinguished Research Prize, GESA | Identification of datasets, cleaning and validating data from Professor Lawrie Powell’s legacy database held at QIMR Berghofer Medical Research Institute | The Liver Foundation, the AusIron network, the International Society for the Study of iron in Biology and Medicine (BioIron), and the European Iron Club. |
| Mr Anthony Marceddo  Edith Cowan University, Perth | ECU Registry design using REDCap, data validation, security and selection of cloud hosting service |  |
| Professor John Olynyk,  Gastroenterologist & Hepatologist,  Fiona Stanley and Fremantle Hospitals WA,  Dean of Clinical Research, School of Medical and Health Sciences,  Health Research Theme Lead, Edith Cowan University  2016 recipient of Distinguished Research Prize, GESA | Consultancy advice on datasets, protocols for adding and accessing data; communication with Primary Health Networks and professional associations including RACGP, ACRRM, GESA and the Australian Rheumatology Association. | Member of Medical and Scientific Advisory Committee for Hemochromatosis Australia and of the Joint Scientific Committee of Haemochromatosis International & the European Federation of Associations of People with Haemochromatosis |
| Professor Martin Delatycki  Medical Director, Victorian Clinical Genetics Services Director, Bruce Lefroy Centre for Genetic Health Research Murdoch Childrens Research Institute, VIC | Consultancy advice on datasets, protocols for adding and accessing data | Member of Medical and Scientific Advisory Committee for Hemochromatosis Australia and of the Joint Scientific Committee of Haemochromatosis International & the European Federation of Associations of People with Haemochromatosis |
| Dr Graeme Carroll Rheumatologist, Fiona Stanley Hospital WA | Consultancy advice on datasets, protocols for adding and accessing data | Member of the international Haemochromatosis Arthropathy Research Initiative |
| Lifeblood | Contact more than 10,000 therapeutic donors and their general practitioners, via its High Ferritin app to communicate the registry and seek participation. |  |