

"New Zealand's peak body representing the entire health and medical research pipeline"

# Health Research Saves Lives Ka Whakarauoratia te Hunga e te Rangahau Hauora



Kiwi family Isabella Powell (back right) with sisters Maggie and Harriet and mum Alley. Demonstrating the life transforming impact of health research on living with Isabella's cystic fibrosis.



Malaghan Institute of Medical Research translational immunology researchers Olivier Gasser and Anna Mooney

Annual Report 30<sup>th</sup> June 2020

## Chair and Chief Executive Report

New Zealanders for Health Research (NZHR)'s vision is improved health and prosperity of New Zealanders through health research. We are New Zealand's peak body representing the entire health and medical research pipeline, and our mission is to:

- Build a society that highly values the benefits delivered by health research in all forms
- Increase the level of investment in health research from all sources government, philanthropy and industry
- Have health and medical research embedded as a key component of New Zealand's health system
- Ensure that New Zealand captures the commercial benefits of investing in health and medical research

Our values comprise inclusion, constructive engagement, independence, being evidence based, and assertiveness.

To this end we are very pleased to report on NZHR's achievements for the year ending 30<sup>th</sup> June 2020. Like most organisations with a similar year end it was a year of two halves with the first six months anticipating the advent of the sentinel 2020 year, and much of the second six months addressing the consequences of the Covid 19 pandemic.

## Annual opinion polling

NZHR's fourth Roy Morgan Research report on its polling of five hundred New Zealanders was published in August 2019. The report once again demonstrated that New Zealanders place a high value on health and medical research, that they support increased investment from government, industry and philanthropy, and that there was a high degree of willingness to participate in health research through clinical trials and sharing of personal information.

The report was sent to key government Ministers, ministry officials, the Prime Minister's Science Advisor and health related departmental science advisors, and conveyed to members and stakeholders through presentation events in Auckland, Wellington, Christchurch and Dunedin.

This was the last of the polls undertaken by Roy Morgan, and NZHR remains indebted to them for their commitment, professionalism and support as a platinum member for the first four years of NZHR's existence.

However, we're delighted to report that we have entered into a three year silver membership arrangement with Kantar, who undertook our fifth poll in May 2020, with results due to be disseminated in July 2020.

## Advocacy and lobbying

Throughout the year, as in previous years, NZHR consistently advocated for government investment in health research to be increased from 0.8% of health care costs to 2.4% within the time frame of the Health Research Strategy.

NZHR has also argued for health research to be embedded as an essential component of the health system in order to save lives and improve health outcomes, drawing attention to the approximately 5000 New Zealanders per year who are dying prematurely and unnecessarily, and the 7000 kiwis who are dying prematurely because we haven't done the research to know how to effectively treat them. This focus is reflected in our decision to change the name of our newsletter from *Health Research Matters* to *Health Research Saves Lives/ Ka Whakarauoratia te Hunga e te Rangahau Hauora*.

We have also sought to leverage the success of New Zealand's health research led response to the threat presented by the Covid 19 pandemic, suggesting that the New Zealand health and disability system could be more effective if it were to be similarly led.

Specific advocacy and lobbying activities included:

Submission on MBIE's discussion paper: Intellectual Property Laws Amendment Bill, arguing that clinical trials contribute significantly to New Zealanders' health and prosperity; incentives to encourage industry investment in clinical trials are significantly outweighed by systemic disincentives, resulting in industry being increasingly disinclined to lift investment in health and medical research in New Zealand; the 2013 Patents Act be amended to make it make it easier for pharmaceutical companies to invest in researching and developing new medicinal uses of known drugs, both in New Zealand and elsewhere.

Responding to the <u>Interim Report of the Health and Disability System Review</u>, expressing extreme disappointment at the lack of any recommendations which would see health research embedded as a core component of a redesigned health system, and astonishment that of the report's 468 citations not one of them referred to the government's Health Research Strategy.

Submission on MBIE's consultation paper: New Zealand's Research, Science & Innovation Strategy, arguing that: the government's aspirational ten year 2% R&D investment target is too low and that the 15% R&D tax incentive is insufficient; R&D investment allocated to health research should at the very least to be associated with a commitment to triennially determined annual increases consistent with the overall 2% target; and that the RSI strategy should support the establishment of new start-up enterprises

Submission to the Ministry for Primary Industries on folic acid fortification maintaining that fortification of flour with folic acid should be supported because it is unequivocally supported by the results of international and New Zealand health research, and it will have a significant impact on the incidence and prevalence of neural tube defects, including spina bifida, resulting in: improved population health

outcomes; a lowering of the burden of disease on society, families and individuals; and reduced health care costs

Responding to Mental Health and Wellbeing Commission Bill submitting both in writing and in person before the Health Committee that: most of the recommendations in He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction were not supported by any referenced evidence; the current level of government investment in mental health and addictions research was about 20% of what it should be; and that the Commission's brief should include management of a new research investment stream comprising no less than 2.4% of the costs of providing publicly funded mental health and addiction services.

Submission on Budget Policy Statement (BPS) 2020, both in writing and in person before the Finance Committee. NZHR's submission was that the BPS should be amended to: increase the \$1.9b four year allocation to improve mental health outcomes by \$140m to \$2.04b, to ensure that there is sufficient provision to carry out much needed, life-saving, mental health research; recognise that improvements in health outcomes should be supported by greater investment in, and better application of the results of, health research; and, send a strong signal that that the 2020 budget will provide for significant increases in health research investment following the overdue HRC Act required triennial review of HRC funding

A request to the Ministry of Health asking that Medsafe's decision to discontinue its practice of granting <u>fee waivers for the assessment of public good clinical trials</u> be reversed.

Responding to the Government's May 2020 Budget expressing concern that government budgeted investment in health research had fallen from 0.81% of health care costs in 2019 to 0.71% in the 2020 budget and arguing that to pull our weight internationally and to serve New Zealanders well New Zealand should be investing at least 2.4%.

#### Covid 19

Although Covid 19 affected NZHR's ability to stage events planned for March 2020 and beyond, we were able to use it as an opportunity to "build a society that highly values the benefits delivered by health research in all forms". We used and grew our social and other media networks to promote the message of "trust the science, stay home, save lives", actively sought to counter media and other grandstanding which we believed could undermine that trust, and monitored and reported on progress on bring Covid 19's prevalence and incidence under control during the initial lockdown period.

## **Health Research Saves Lives**

We continued to publish a regular newsletter to keep approximately 900 stakeholders and NZHR members both informed as to the development of NZHR and apprised of national and international developments relevant to health research in New Zealand.

## Membership

Douglas Pharmaceuticals, Multiple Sclerosis New Zealand, the Multiple Sclerosis Research Trust and Kantar were welcomed as NZHR members during the period, joining existing members University of Otago, Cure Kids, Malaghan Institute for Medical Research, Victoria University of Wellington, Massey University, Merck Sharpe and Dohme NZ, Roche Products NZ, AbbVie NZ, the New Zealand Association of Clinical Researchers (NZACRes), AUT, Middlemore Clinical Trials and Research Australia. We also acknowledge the support of foundation members Auckland Medical Research Foundation and the Bupa Foundation.

Thanks too for the support of the NZHR Board who represent a cross section of NZHR members, and we also gratefully acknowledge the support of NZHR's inaugural patron Bruce Scoggins.

### **Finances**

NZHR's year-end financial position is satisfactory. We continue to rely on growth from, and be grateful for, the financial contributions of NZHR members which has enabled us to realise the achievements outlined above.



Graham Malaghan Chairperson



Chris Higgins Chief Executive

## New Zealanders for Health Research Board



Graham Malaghan

Chair (from 14<sup>th</sup> December 2015; reappointed 25<sup>th</sup> November 2016; reappointed 10<sup>th</sup> October 2019)



Frances Benge

CEO - Cure Kids (from 14<sup>th</sup> December 2015; reappointed 12<sup>th</sup> October 2017)



**Paul Smith** 

Country Director -Merck, Sharp & Dohme NZ (from 14<sup>th</sup> December 2015; reappointed 11<sup>th</sup> October 2018)



Dr Martin Gagnon

Director of Research and Enterprise -University of Otago (from 11<sup>th</sup> October 2018)



Nadia Levin

CEO - Research Australia (from 14<sup>th</sup> December 2015; reappointed 25<sup>th</sup> November 2016; reappointed 10<sup>th</sup> October 2019)



**Prof Lindsey White** 

Associate Dean (Research and Enterprise), Faculty of Health and Environmental Sciences, AUT (from 11<sup>th</sup> July 2019)



**Prof David Harper** 

Dean of Science Wellington Faculty of Science Victoria University of Wellington (from 27<sup>th</sup> February 2019)



**Peter Surman** 

Chief Scientific Officer, Douglas Pharmaceuticals (from 10<sup>th</sup> October 2019)

## **Patron**



Bruce Scoggins (from 10<sup>th</sup> October 2019)

## Statement of Service Performance 2020

Vision: improved health and prosperity of New Zealanders through health research

Goal: to make health research a higher priority, attracting greater investment from government, industry and philanthropic organisations.

At its February 2017 meeting the NZHR identified a set of success measures and targets to assist in identifying the extent to which the organisation has been making an impact in respect of the strategies included in its strategic and operating plans. The set of measures has been reviewed and updated in successive strategic plans.

Measures for which data is available are presented on the following table<sup>1</sup>:

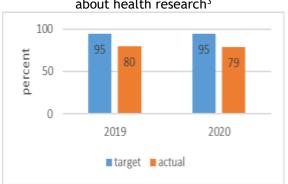
Strategy: Mobilise public support for health research

## Impact measures<sup>2</sup>

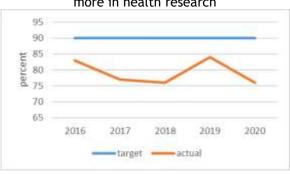
Percentage who say that they are well informed about health research



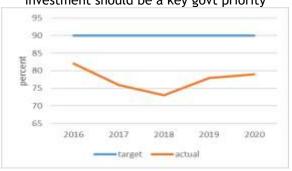
Percentage who are well informed about health research<sup>3</sup>



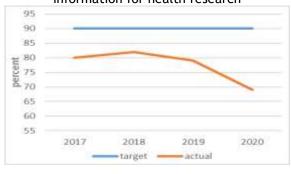
Percentage who agree that govt should invest more in health research



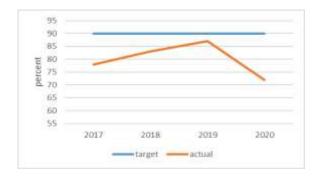
Percentage who agree that health research investment should be a key govt priority



Percentage willing to share personal health information for health research



Percentage willing to participate in clinical trials



<sup>&</sup>lt;sup>1</sup> NZHR's 2020/21 work plan addresses areas where performance and impact fall short of targets

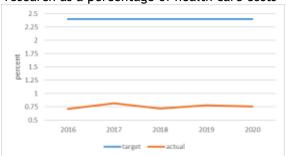
<sup>&</sup>lt;sup>2</sup> NZHR. New Zealand Speaks! Opinion polls 2016 - 2020

<sup>&</sup>lt;sup>3</sup> NZHR PUHRR (personal understanding of health research results) index = average agreement with eight health research validated safe and effective measures for improving health outcomes comprising: vaccinations; fluoride in public water supplies; folic acid in flour; genetically modifying organisms to make new medicines; eating fruit and vegetables; regular exercise; reducing sugar intake; and reducing salt consumption

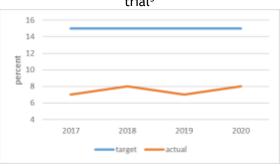
## Strategy: Increase health research investment

### Impact measures

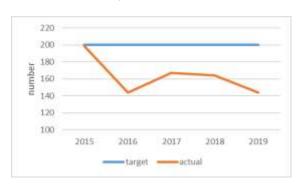
Ringfenced government investment in health research as a percentage of health care costs<sup>4</sup>



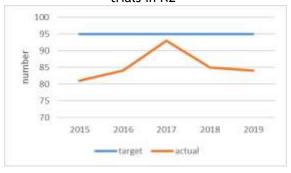
Percentage who have participated in a clinical trial<sup>5</sup>



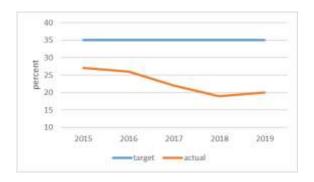
Number of industry funded clinical trials in NZ<sup>6</sup>



Number of non-industry non-DHB funded clinical trials in  ${\rm NZ}^7$ 



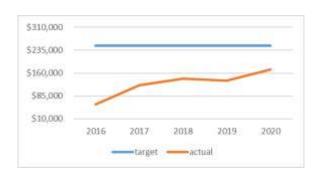
Australasian market share8



## Strategy: Build a sustainable and effective organisation

## Impact measure

#### Membership derived revenue



<sup>&</sup>lt;sup>4</sup> NZ Treasury Budget estimates 2016 - 2020

<sup>&</sup>lt;sup>5</sup> NZHR. New Zealand Speaks! Opinion polls 2017 - 2020

<sup>6</sup> HDEC

<sup>7</sup> HDEC

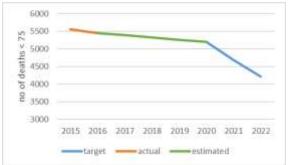
<sup>&</sup>lt;sup>8</sup> Commercially funded trials in NZ as percentage of Australia + NZ total. ANZCTR online database

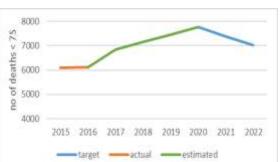
#### **Strategy:** Embed health research as an essential component of New Zealand's health system

## Impact measures9

Premature amenable mortality<sup>10</sup>

Premature non-amenable mortality<sup>11</sup>





New impact measures introduced as part of NZHR 2020 - 23 strategic plan
 https://nsfl.health.govt.nz/dhb-planning-package/system-level-measures-framework/data-support-system-level-measures/amenable.
 https://www.health.govt.nz/publication/mortality-2017-data-tables
 and earlier tables

# Partners and supporters

**Platinum** 





Gold







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Chrome





**Foundation** 







Pro bono legal services

Russall McCaagh