

10 September 2026

**Hon Simeon Brown**

Minister of Health

**Hon Cameron Brewer**

Minister of Commerce and Consumer Affairs

Parliament Buildings

Wellington

Tēnā kōrua Ministers

## **URGENT: PLEASE COMMENCE CONSULTATION ON GENETIC DISCRIMINATION IN INSURANCE**

We write on behalf of Against Genomic Discrimination Aotearoa (AGenDA), a broad coalition of health professionals, researchers, legal experts, patient organisations and people with lived experience.

On 19 August, AGenDA briefed the Health Committee and asked it to recommend that consultation under sections 83–85 of the Contracts of Insurance Act 2024 commence before the end of 2026.

Our request to you is equally straightforward: please make the decision to begin consultation.

A predictive genetic test identifies an increased risk of disease; it is not a diagnosis. Testing can enable earlier screening, surveillance, preventive medication, risk-reducing surgery and testing of other family members. It can also guide treatment and determine access to particular therapies and clinical trials.

Yet insurers can use these results to increase premiums, exclude related conditions, restrict cover or decline an application. Some people are therefore paying higher premiums while claims connected with the same risk are excluded, effectively paying more for less protection.

The current system creates a perverse incentive: the person who follows medical advice, gets tested and reduces their risk may be penalised, while someone with the same underlying risk who remains untested may receive standard terms.

Comparable OECD countries have recognised and addressed this conundrum through legislation, regulation, moratoria or binding codes. New Zealand has not, along with Colombia and Costa Rico.

International and local evidence shows that insurance concerns may cause 10–30 percent of people to delay or decline testing or participation in genomic research. The result is lost opportunities for prevention, later diagnosis, longer diagnostic journeys, and people being unable to access the clinical options most relevant to their condition. The downstream costs are then borne by individuals, families and the public health system.

We recognise the concern that restricting insurers' use of genetic test results could lead to higher premiums for other policyholders. However, that outcome has not been demonstrated in countries with longstanding protection. Research and experience from the United Kingdom and Canada have not shown a significant adverse effect on insurance markets or a material market-wide premium impact. Nor was this seen while Australia's moratorium was in place.

Ordinary underwriting would continue. Insurers could still consider diagnosed disease, symptoms, treatment and other established risk factors. Protecting predictive test results would not turn insurance into a guaranteed-issue product.

Insurers also stand to benefit. Prevention, earlier diagnosis and risk-reducing intervention can reduce the incidence and severity of future claims. Clear rules would improve consistency, strengthen consumer confidence and reduce disputes and reputational risk. Any remaining actuarial concerns should be tested through consultation, not assumed in the absence of evidence.

### **The timing is now critical:**

- It is almost two years since Parliament created the legal mechanism for regulating insurers' use of genetic-test results.
- It is one year since MBIE's planned consultation was paused. The policy framework and consultation document already exist. The Health Committee's briefing remains open, while the House is expected to adjourn on 24 September and Parliament to dissolve on 1 October.
- Australia's statutory protection takes effect on 8 October 2026, while New Zealand's Contracts of Insurance Act must be fully in force by 15 November 2027.

### **We therefore ask you to:**

1. Confirm before the House rises that consultation will commence before the end of 2026; and
2. Direct MBIE, working with the Ministry of Health, to release the consultation document and assess the preventive, health-system and insurance benefits, including the evidence concerning any wider impact.

Consultation does not prejudice the final model. It is how the evidence is tested, competing interests are weighed, and workable protections are developed.

The legal mechanism exists. The consultation document exists. The evidence exists. What is now required is the political decision to begin.

A genetic test should be a tool for prevention, not the basis for penalising someone who gets tested and acts to reduce their risk while offering standard terms to someone with the same underlying risk who remains untested.

Ngā mihi nui,

Professor Andrew Shelling and Fay Sowerby

Co-Leads  
Against Genomic Discrimination Aotearoa (AGenDA)

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This request to commence consultation is supported by the organisations and individual AGenDA members listed in Appendices 1–3.

## Appendix 1

### Organisational supporters of the commencement of consultation

The organisations below support the timely commencement of consultation under sections 83–85 of the Contracts of Insurance Act 2024.

|                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                               |
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|  <p><b>Chris Higgins</b><br/>Chief Executive<br/>Rare Disorders New Zealand<br/><small>Together with 33 named rare-disorder organisations and support groups</small></p> |  <p><b>Nicola Coom</b><br/>Chief Executive   Tumu Whakarae<br/>Cancer Society of New Zealand</p>                                                 |  <p>Breast Cancer<br/>Foundation NZ<br/><b>Vanessa Sorenson</b><br/>Incoming CEO<br/>Breast Cancer Foundation NZ</p>                                                                                                     |
|  <p><b>Tim Edmonds</b><br/>CEO<br/>Blood Cancer NZ</p>                                                                                                                   |  <p><b>Peter Huskinson</b><br/>Chief Executive<br/>Bowel Cancer New Zealand</p>                                                                  |  <p>New Zealand Familial Breast &amp; Ovarian Cancer Trust<br/>Te Pou Mānaki Whānau Māte ā-roa pūhupuku o Aotearoa<br/><b>Dr Simone Petrich</b><br/>Chair<br/>New Zealand Familial Breast &amp; Ovarian Cancer Trust</p> |
|   <p><b>Anna-marie Ruhe</b><br/>Tumuaki / Chief Executive<br/>Hei Ahuru Mōwai</p>     |  <p><b>Te Ira Tātai Whakaheke</b><br/>National Centre of Māori<br/>Genomics &amp; Research<br/><b>Professor Phillip Wiltcox</b><br/>Co-Chair</p> |  <p>PATIENT VOICE AOTEAROA<br/><b>Malcolm Mulholland</b><br/>Chair<br/>Patient Voice Aotearoa</p>                                                                                                                        |

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|  <p><b>Julia Mansour</b><br/>Chief Executive<br/>Human Genetics Society of Australasia</p>     |  <p><b>Dr James Liang</b><br/>New Zealand Councillor<br/>Haematology Society of Australia and New Zealand</p>           |  <p><b>Dr Sharon English</b><br/>Chair, Aotearoa New Zealand National Committee<br/>Te Whare Piki Ora o Māhutaonga – Royal Australasian College of Surgeons</p> |
|  <p><b>Daniel Conway</b><br/>Head of Legal Services<br/>The Law Association of New Zealand</p> |  <p><b>Dr Graeme Jarvis</b><br/>Chief Executive<br/>Medicines New Zealand</p>                                           |  <p><b>Letitia Harding</b><br/>CEO<br/>The Cardiac and Respiratory Foundation NZ</p>                                                                            |
|  <p><b>Susan Martin</b><br/>General Manager, Australia and New Zealand<br/>illumina</p>        |  <p><b>Gretchen Weightman</b><br/>Vice President and General Manager, Asia Pacific<br/>Oxford Nanopore Technologies</p> |  <p><b>Tony Lough</b><br/>VP Clinical Science<br/>Pacific Edge Cancer Diagnostics</p>                                                                           |
|  <p><b>Liz Pennington</b><br/>CEO<br/>Ovarian Cancer Foundation NZ</p>                       |  <p><b>Libby Burgess</b><br/>Chair<br/>Breast Cancer Aotearoa Coalition</p>                                           |  <p><b>Chris Tse</b><br/>Trustee<br/>Lynch Syndrome Support/<br/>Brain Tumour Support</p>                                                                     |

Organisational names and logos are reproduced with the approval of the relevant organisations. Support relates to commencement of consultation under sections 83–85 of the Contracts of Insurance Act 2024.

## Appendix 2 — Rare-disorder organisations and support groups

Rare Disorders New Zealand and 33 named rare-disorder organisations and support groups within the AGenDA coalition.

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|--------------------------------------------------|--------------------------------------------------------------------------|----------------------------------------------------|
| 1. 22q Foundation Australia and New Zealand      | 12. Friedreich's Ataxia Research Association New Zealand (FARA)          | 23. ITP Australia/New Zealand                      |
| 2. New Zealand Pompe Network                     | 13. Spinal Muscular Atrophy New Zealand                                  | 24. Hirschsprung's Disease Support New Zealand     |
| 3. Charcot-Marie-Tooth support group             | 14. EGPA / Churg Strauss New Zealand                                     | 25. VHL New Zealand                                |
| 4. Motor Neurone Disease New Zealand             | 15. New Zealand Prader-Willi Association                                 | 26. Haemophilia Foundation of New Zealand          |
| 5. ausEE Inc.                                    | 16. Ehlers-Danlos Syndromes New Zealand                                  | 27. Tuberous Sclerosis Complex New Zealand (TSCNZ) |
| 6. Myasthenia Gravis Support Group               | 17. PNH Support Association of New Zealand                               | 28. HAE Australasia Ltd                            |
| 7. New Zealand Amyloidosis Patient Association   | 18. NZ Dystonia Community                                                | 29. The Arthrogryposis Group New Zealand (TAG-NZ)  |
| 8. Muscular Dystrophy Association of New Zealand | 19. New Zealand Down Syndrome Association                                | 30. Fragile X New Zealand Trust                    |
| 9. The New Zealand Acromegaly Society            | 20. UNIQUE — Rare Chromosome Disorder Support Group                      | 31. HHT NZ                                         |
| 10. ANCA Vasculitis NZ support group             | 21. Kiwi CRPS Charitable Trust                                           | 32. Fabry NZ                                       |
| 11. NZ Still's support group                     | 22. International Waldenström's Macroglobulinemia Foundation New Zealand | 33. Foetal Anti-Convulsant Syndrome NZ             |

Note: This list reflects the rare-disorder organisations and support groups supplied to AGenDA for this communication.

## Appendix 3 — Individual AGenDA supporters by institution or affiliation

*The following people confirmed that their names could be used in support of commencing consultation.*

### University of Auckland-affiliated individual members

- Stefan S. Bohlander — Professor, Leukemia and Blood Research, Scientific Director Grafton Clinical Genomics, Department of Molecular Medicine and Pathology
- Peter J. Browett — Professor of Pathology and Consultant Haematologist, Blood Cancer NZ Research Unit, Department of Molecular Medicine and Pathology, Auckland City Hospital
- Ofa Dewes — Research Fellow, Faculty of Arts and Education / Compass
- Rob Doughty — Professor, Heart Foundation Chair of Heart Health
- Mark Henaghan — Professor, Faculty of Law
- Kimiora Henare — Senior Research Fellow, School of Medical Sciences, Faculty of Medical and Health Sciences
- Jaime S. King — Professor, University of Auckland, Faculty of Law, Chair in Health Law
- Ben Lawrence — Associate Professor, Head of Department, Department of Cancer Sciences, Faculty of Medical and Health Sciences, New Zealand
- Klaus Lehnert — Professor, Centre for Brain Research and School of Biological Sciences
- Rinki Murphy — Professor of Medicine, Monogenic diabetes guidance group chair, New Zealand Society for the Study of Diabetes, Department of Medicine, School of Medicine
- Justin O’Sullivan — Professor and Director, Liggins Institute
- Cristin G. Print — Professor, Department of Molecular Medicine and Pathology, Faculty of Medical and Health Sciences
- Ann Rolleston — Managing Director, The Centre for Health, Faculty of Medical and Health Sciences
- Andrew N. Shelling — Professor, Department of Obstetrics and Gynaecology, Faculty of Medical and Health Sciences
- Russell G. Snell — Professor, Centre for Brain Research and School of Biological Sciences
- Andrew Sporle — Associate Professor (Honorary), Department of Statistics, Managing Director, iNZight Analytics Limited, Horizon Europe research fund, Ministry of Business, Innovation and Employment and New Zealand delegate to the Global Programme on Artificial Intelligence, OECD, Expert Advisor, Artificial Intelligence Audit Panel, Independent Programme on the Information Environment, Switzerland.
- Nikki Earle — Heart Foundation-Hynds Senior Research Fellow, Department of Medicine
- Dame Juliet Gerrard — Professor

### University of Otago-affiliated individual members

- Louise S. Bicknell — Professor, Department of Biochemistry, Genetics of Rare Disorders, Dunedin
- Vicky A. Cameron — Emeritus Professor, Christchurch
- Jon Cornwall — Programme Director, Education Advisor, Senior Lecturer, Centre for Early Learning in Medicine, Dunedin
- Sara K. Filoche — Associate Professor, Department of Obstetrics, Gynaecology and Women’s Health, Wellington
- Parry J. Guilford — Professor and Director, Cancer Genetics Laboratory, Department of Biochemistry, Dunedin
- Martin A. Kennedy — Professor, Department of Pathology and Molecular Medicine, Director Gene Structure and Function, Carney Centre for Pharmacogenomics, Christchurch
- Lisa Matisoo-Smith — Distinguished Professor, Biology and Anthropology, Dunedin
- Helen Morrin — Curator Cancer Society Tissue Bank, Science Policy Steering Committee, International Society of Biological and Environmental Repositories Department of Pathology and Molecular Medicine, Christchurch.
- Rachel V. Purcell — Department of Surgery, Christchurch
- Stephen P. Robertson — Professor, Department of Paediatrics and Child Health, Faculty of Medicine, Dunedin
- Bridget A. Robinson — Emeritus Professor, University of Otago, Christchurch
- Ben Te Aika — Professor, Iwikau Te Aikā, Kāti Urihia Hapū, Te Waipounamu
- Logan C. Walker — Professor Department of Pathology and Biomedical Science, Associate Dean Research, Co-Director Genetics, Otago, Christchurch
- Phillip L. Wilcox — Prof Phillip Wilcox, Dept Mathematics and Statistics University of Otago, Co-Chair Te Ira Tātai Whakaheke Charitable Trust
- Anna Pilbrow — Deputy Head of Department and Research Associate Professor, Christchurch Heart Institute, Christchurch

### University of Waikato-affiliated individual members

- Maui Hudson — Professor and Director, Te Kotahi Research Institute / Office of the Deputy Vice-Chancellor Māori
- Irene Kereama-Royal — Senior Research Fellow & PhD Candidate, Trustee of Hei Ōranga Ū Māori Women’s Breast Cancer Research Trust and Executive Board Secretariat, Te Ira Tātai Whakaheke National Centre of Māori Genomics & Research.
- Karen Turanga — MSocSc Social Policy student

### Monash University - affiliated individual members

- Paul Lacaze — Professor, School of Public Health and Preventive Medicine
- Jane M. Tiller — Associate Professor, School of Public Health and Preventive Medicine

### Other universities and research institutions

- Chris Puliueva — Senior Lecturer – Immunology, Biomedical, Chemical & Food Sciences, School of Science, Women’s Health and Neuroscience Research Programme, Auckland University of Technology, School of Science
- Sophie Hargreaves — Victoria University of Wellington, Faculty of Law (Honours Student)
- Donia Macartney-Coxson — PHF Science, Human Genomics,
- Alison McEwen — University of Technology Sydney, Professor of Genetic Counselling.

## Genetic Health Service New Zealand – affiliated individual members

- Emma Felix — Senior Genetic Counsellor, Wellington
- Harry G. Fraser — Genetic Counsellor, Auckland
- Kimberley Gamet — Service Clinical Director/Senior Genetic Counsellor, Auckland
- Jo Martindale — Head of Molecular Section, Wellington Regional Genetics Laboratory, Wellington
- Katherine Neas — National Clinical Director, Wellington

## Clinical and medical specialists

- Rinki Murphy — Professor, Endocrinologist, Monogenic diabetes clinic, Auckland Diabetes Centre, Health New Zealand
- Simone Petrich — Gynaecologist, obstetrician and breast surgeon, Southern
- Mr. Adam Stewart BMBS FRACS, Consultant Breast Cancer Surgeon Hamilton, Waikato
- Michelle Wilson — Medical Oncology, Auckland

## Human Genetics Society of Australasia

- Lauren Hunt — Chief Operations Officer and Genetic Counsellor
- Julia Mansour — Chief Executive and Genetic Counsellor

## Cancer, health and patient organisations

- Jody Bews-Hair — Trustee, NZ Familial Breast & Ovarian Cancer Trust
- Simone Brown — CEO, Cystic Fibrosis New Zealand
- Libby Burgess — Chair, Breast Cancer Aotearoa Coalition
- Sonja de Mari — CEO, Breast Cancer Cure
- Fay Sowerby — Chair Breast Cancer Cure and Secretary, Breast Cancer Aotearoa Coalition
- Catrin Devonald — CEO, Sweet Louise
- Alicia Didsbury — Ovarian Cancer Foundation New Zealand
- Katrine Evans — Chair, Privacy Foundation NZ
- Liz Pennington — CEO and Lived Experience Lead Facilitator, Ovarian Cancer Foundation New Zealand
- Tim Edmonds — Blood Cancer New Zealand
- Lisa Foster — Home and Community Health Association
- Peter Huskinson — Bowel Cancer New Zealand
- Letitia Harding — CEO, The Cardiac and Respiratory Foundation NZ
- Chris Higgins — Rare Disorders New Zealand
- Denise Lemmen — Administrator, Metavivors NZ and Committee Member, Breast Cancer Aotearoa Coalition
- Andrea Newland — CEO, Melanoma New Zealand
- Anna-marie Ruhe — CEO, Hei Āhuru Mōwai
- Vanessa Sorenson — Incoming CEO, Breast Cancer Foundation New Zealand
- Michelle Sullivan — CEO, Neuroendocrine Cancer New Zealand
- Chris Tse — Lynch Syndrome New Zealand / Brain Tumour Support New Zealand
- Malcolm Mulholland — Patient Voice Aotearoa

## Individual, patient and whānau advocates

- Susanne Ames, Rachel Brown, David Downs, Edward Lee, Louise Anne Malone

**Affiliation note:** Affiliations are provided for identification only and do not imply institutional endorsement unless the organisation also appears in the organisational supporter grid.

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