

# EPIDERMOLYSIS BULLOSA IN NEW ZEALAND

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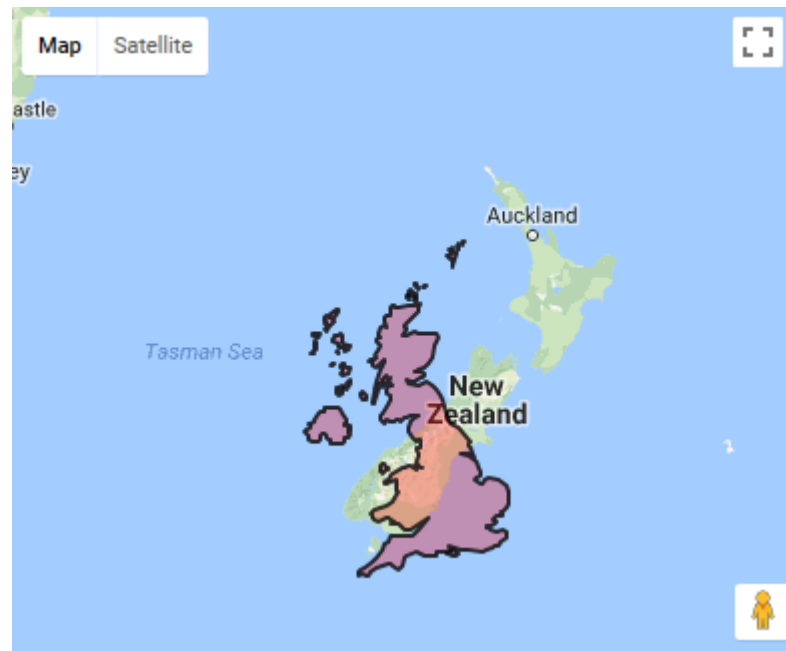


## United Kingdom

- 243,610 sq km
- 65.6 million people

## New Zealand

- 268,838 sq km
- 4.6 million people









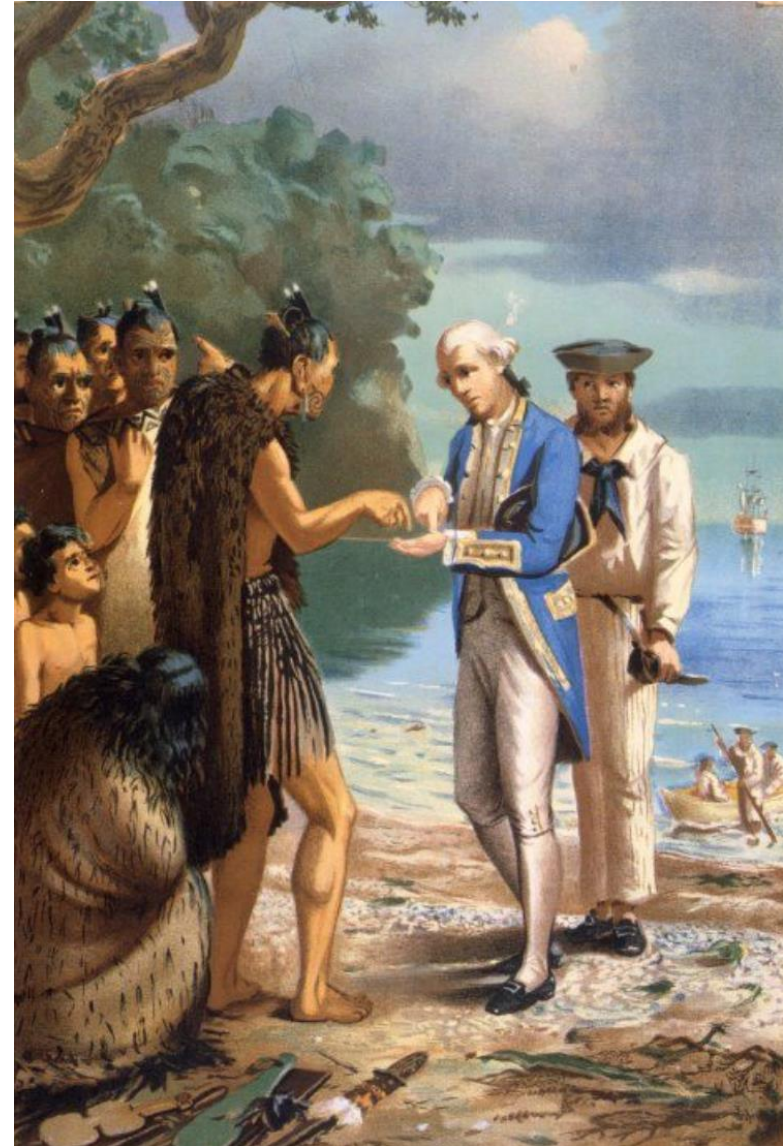
# AOTEAROA – the land of the long white cloud









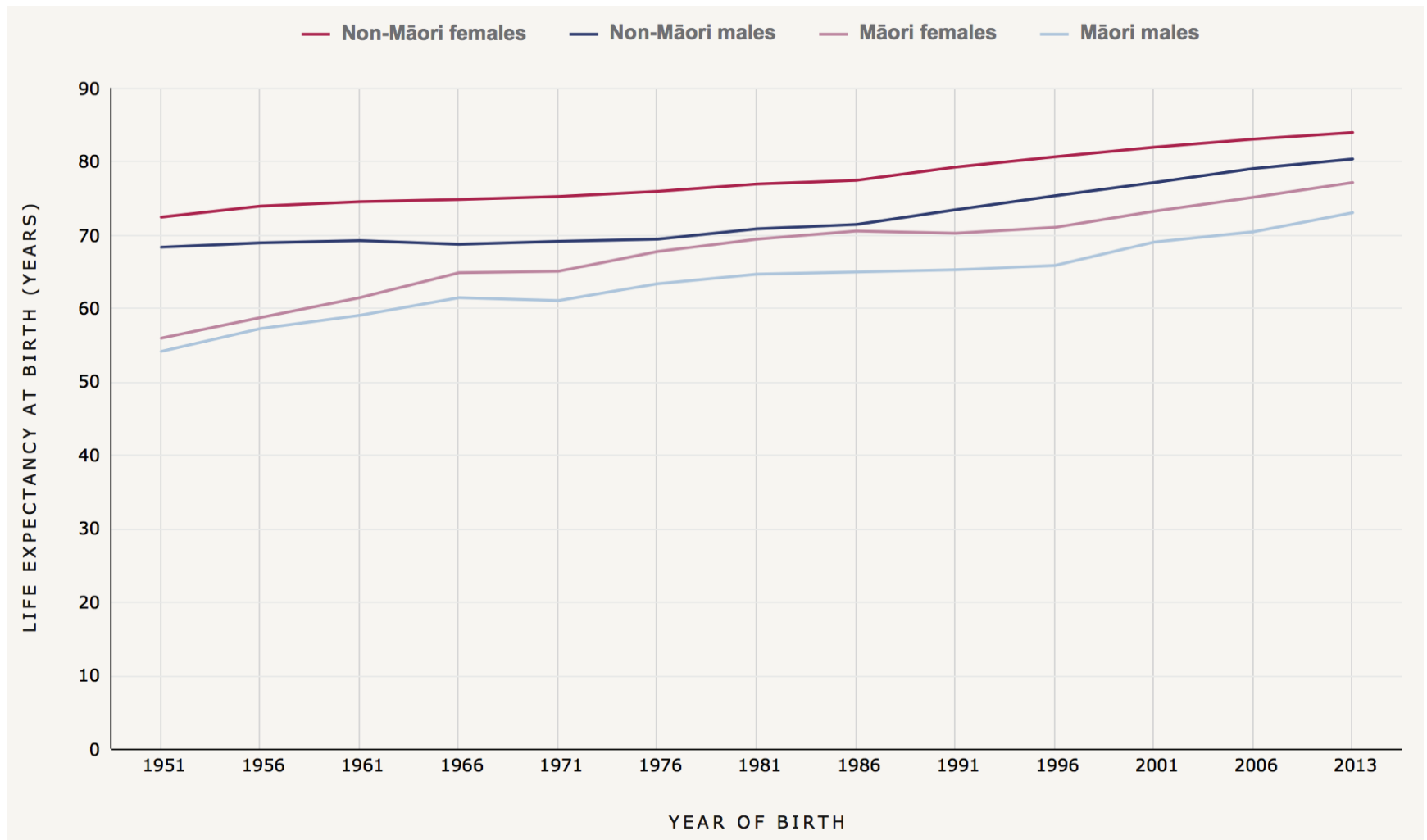




# The Treaty of Waitangi



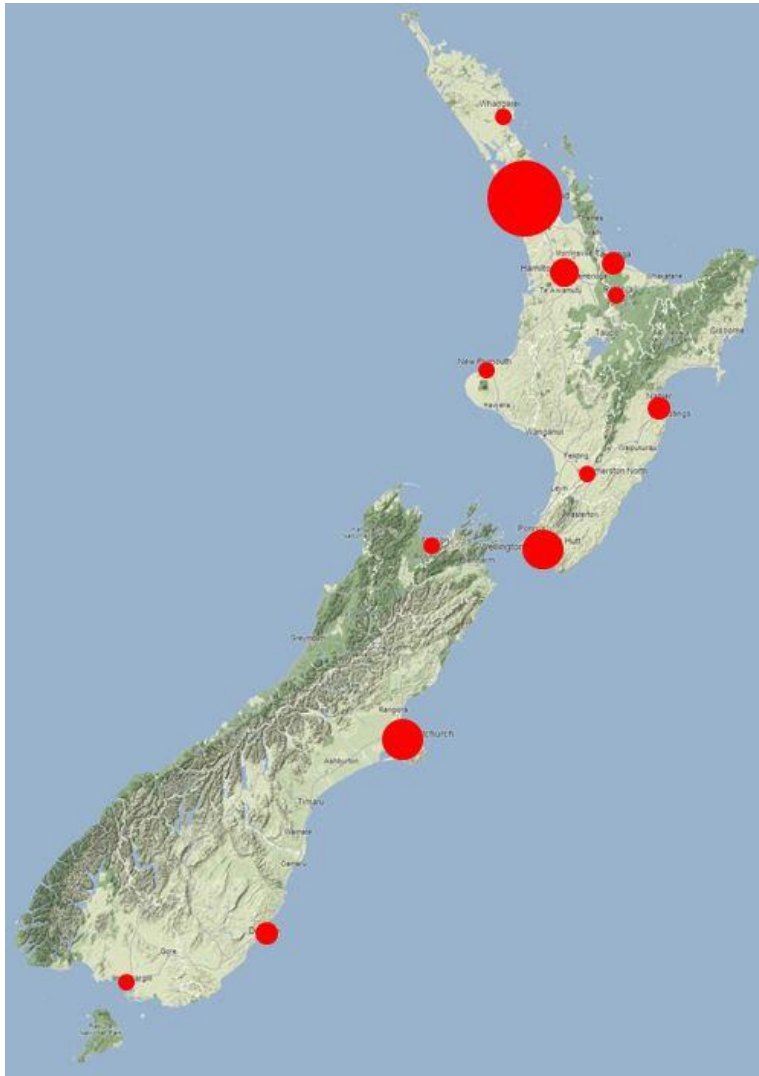
# Life expectancy



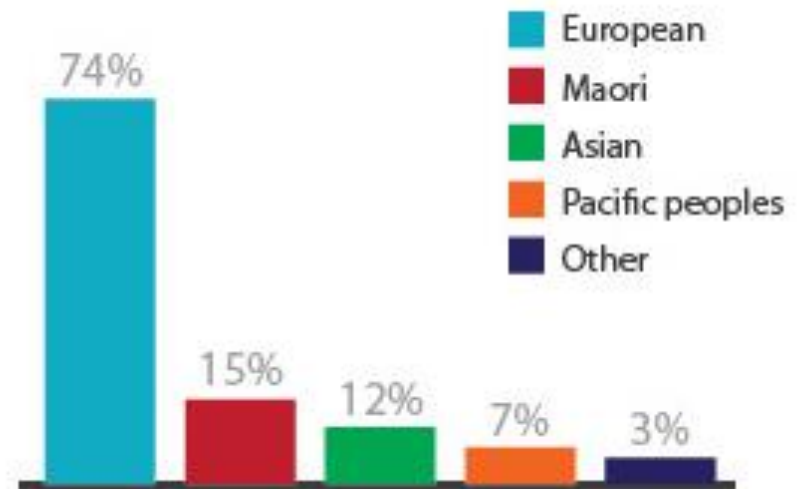


# Maori health





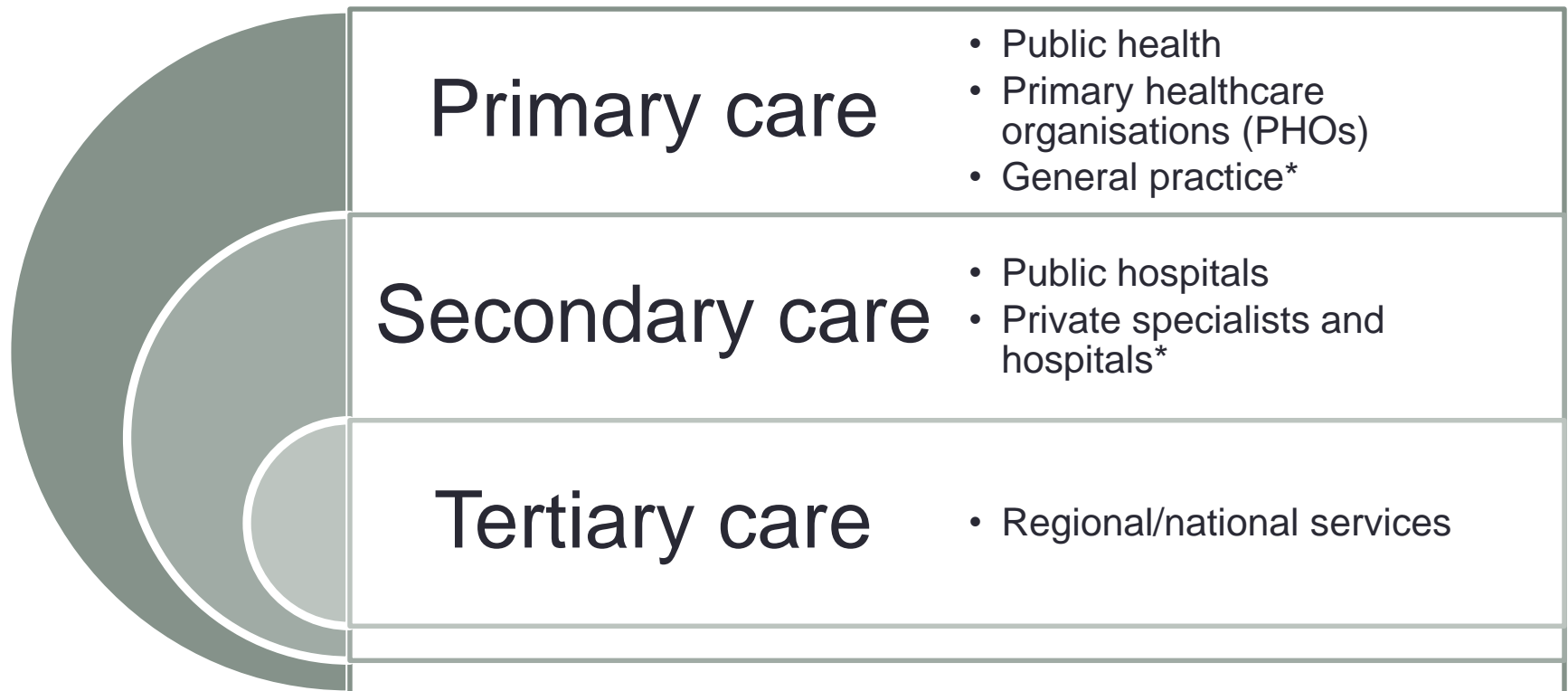
## Ethnic groups (from 2013 Census) \*



\* People who identify with more than one ethnic group are included in each ethnic population, so percentages add up to more than 100.

# New Zealand healthcare system

- National healthcare system funded through taxation
- Broadly similar to the NHS in the United Kingdom



# District health boards

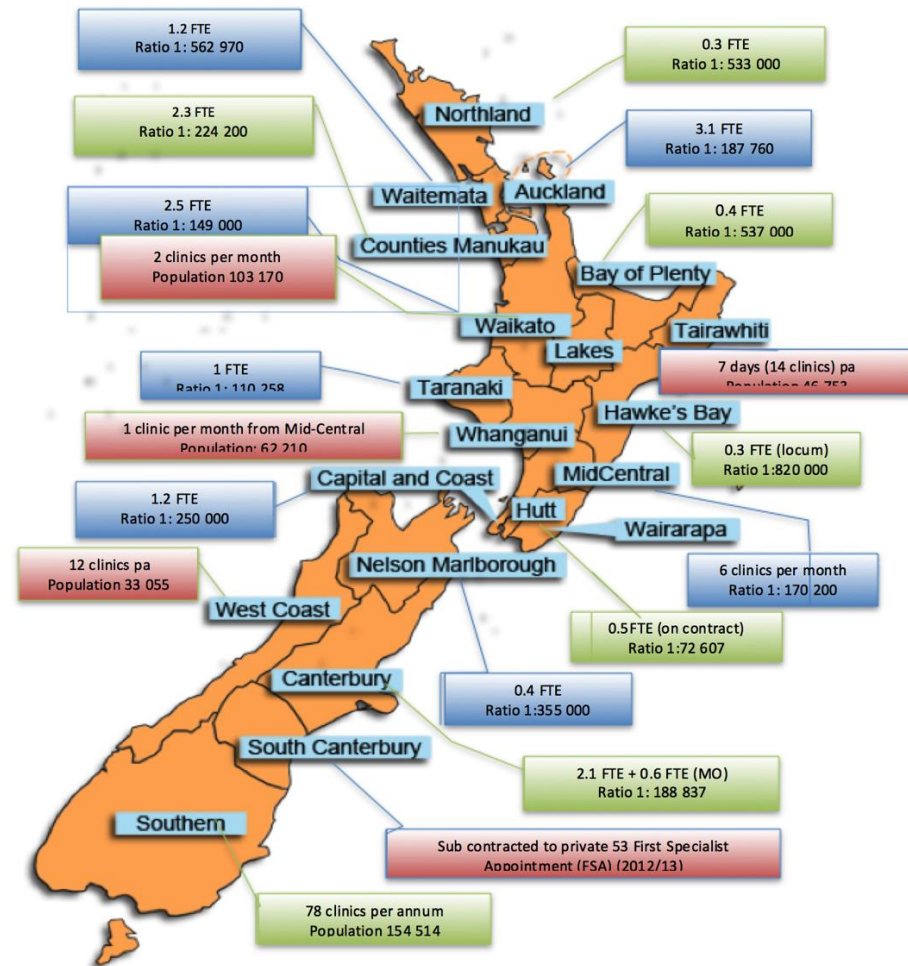
- 20 DHBs receive population based funding to provide
  - Secondary hospital services
  - Primary Healthcare Organisations
- Tertiary services contracted from other DHBs





# Dermatology in NZ

- 61 dermatologists
- Only 16 full time equivalent dermatologists in public hospital work
- High rates of skin cancer
- Limits access for patients with skin disease



2013 data



- National tertiary/quaternary children's hospital

- 219 beds
- Treats 100,000 children per annum

- Paediatric subspecialties

- Medical, surgical, cardiac, transplant subspecialties

- Paediatric dermatology

- EB clinics
- Work with genetics, dentistry, ophthalmology, neonatology, cultural support, palliative care

- Advice for dermatologists and paediatricians nationally and internationally





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  - 219 beds
  - Treats 100,000 children per annum
- Paediatric subspecialties
  - Medical, surgical, transplant subspecialties
- Paediatric dermatology
  - EB clinics
  - Work with genetics, dentistry, ophthalmology, neonatology, cultural support
- Supported by EB experts internationally



# EB in New Zealand



- Total: 117 people with EB
  - 42 EBS
  - 9 EBS-DM
  - 12 RDEB
  - 39 DDEB
  - 3 JEB non Herlitz
  - 12 non-classified

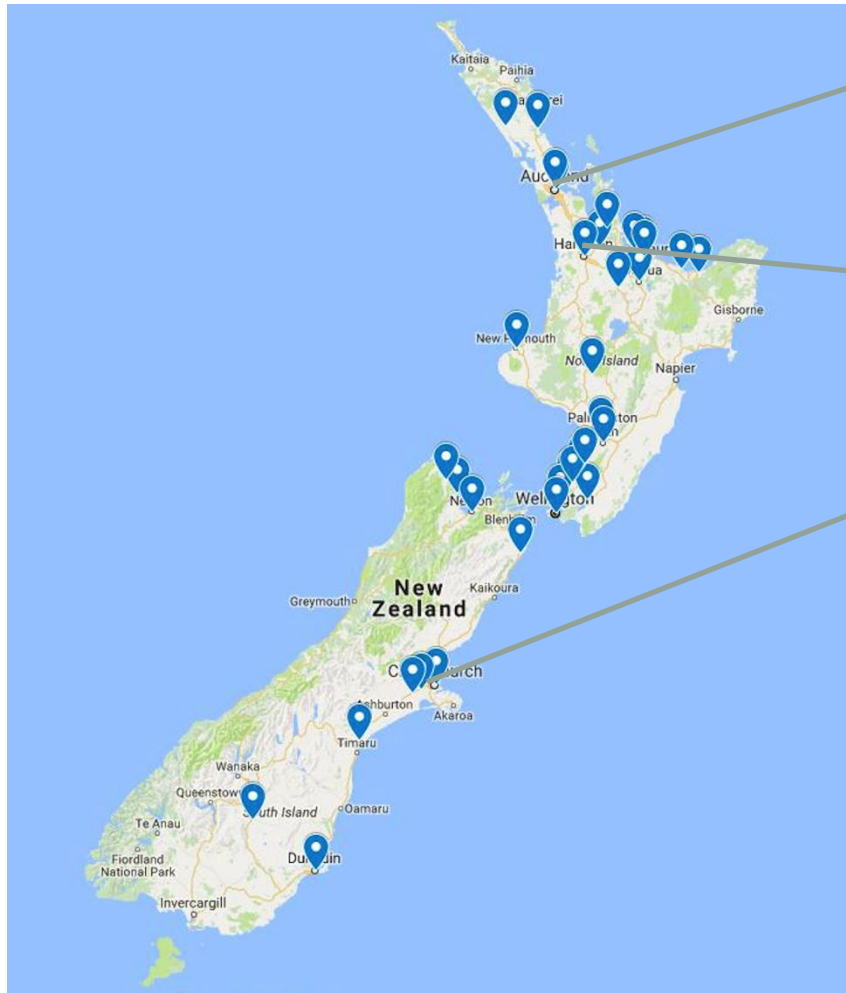


# EB in New Zealand



- Total: 117 people with EB
  - 42 EBS
  - 9 EBS-DM
  - 12 RDEB
  - 39 DDEB
  - 3 JEB non Herlitz
  - 12 non-classified
- Infants
  - 5 JEB with pyloric atresia
  - 3 Herlitz JEB

# EB nursing service



- Jacqui

- Jane

- Sharon

- Established by Debra NZ in 2002
- Clinical advice and support
- Home and hospital visits



**CARE OF NEWBORN INFANT WITH SUSPECTED  
EPIDERMOLYSIS BULLOSA [EB]**



- Aims:
  - To support DEBRA families – practical, financial, emotional support
  - To ensure current best practice care advice is shared with clinicians and families
    - Saline bathing
    - Specialised dressing rooms







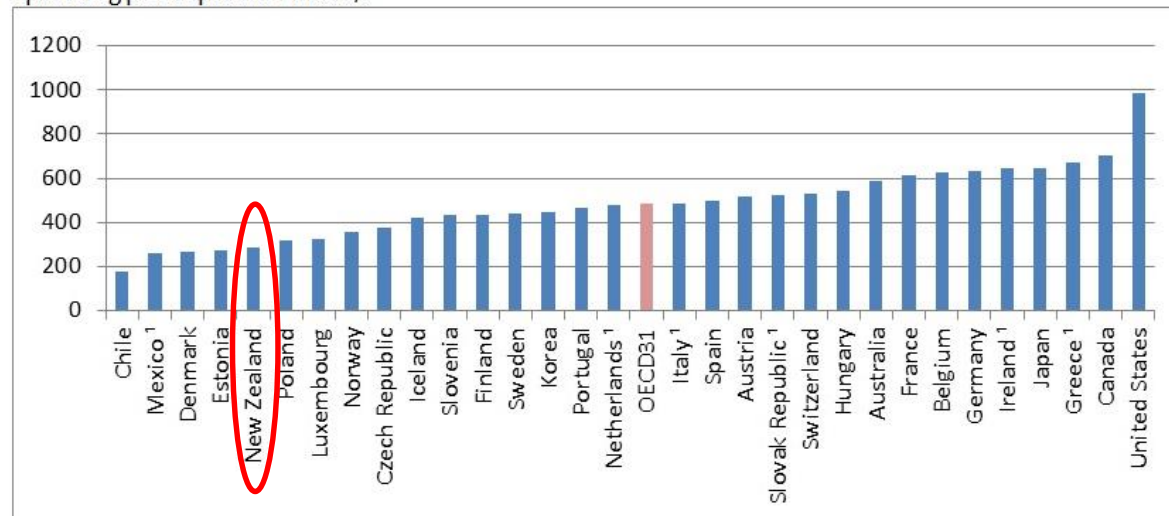
# PHARMAC

Pharmaceutical Management Agency

- Aims to get best health outcomes from pharmaceutical treatments within government budget
- Process of managed schedule of medications and competitive tendering from pharmaceutical companies

The US spends more on drugs

Spending per capita in PPPUS\$:



# Bandaging for EB

- People with EB can access a range of listed wound care products
- Funded out of DHB budgets
- Issues with
  - Variable access across DHBs
  - Optimising orders
  - Minimising waste



# Christchurch earthquake 2011



- 185 people killed
- Many buildings destroyed
- Severe disruption to infrastructure
- No access to deliveries or pharmaceuticals for days
- Highlighted need for emergency planning

# Challenges for EB in New Zealand

## Challenges

- Small patient population
  - Geographic distance
  - Maintaining clinical skills
- Engaging with patients and clinicians
  - Late presentation of problems
- Advances in care – increasing costs

## Opportunities

- Utilise technology
- Collaborate with international experts
- Improve awareness of EB best practice
- Centralised multidisciplinary clinic
- Evidence based practice
- Participation in research



