Aspects of Genetics: A Health Research Perspective

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Privacy Forum, March 2003, Wellington

Bruce A Scoggins PhD:
A biographical sketch

- Chief Executive of HRC (1991 – Present)
- Gordon Meiklejohn Professor of Medicine at University of Colorado Health Sciences Center, Denver, USA (1989-1991)
- Senior Principal Research Fellow of NHMRC at Howard Florey Institute of Experimental Physiology and Medicine, University of Melbourne (1964-1989)
- Current Interests: Health research policy (national and regional), regulation of new technologies, ethics

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For Discussion

- Genetics in a global context of scientific discovery
- Examples of New Zealand research at the cutting edge
- Regulation of genetic research
- Challenges for tomorrow which we need to address today

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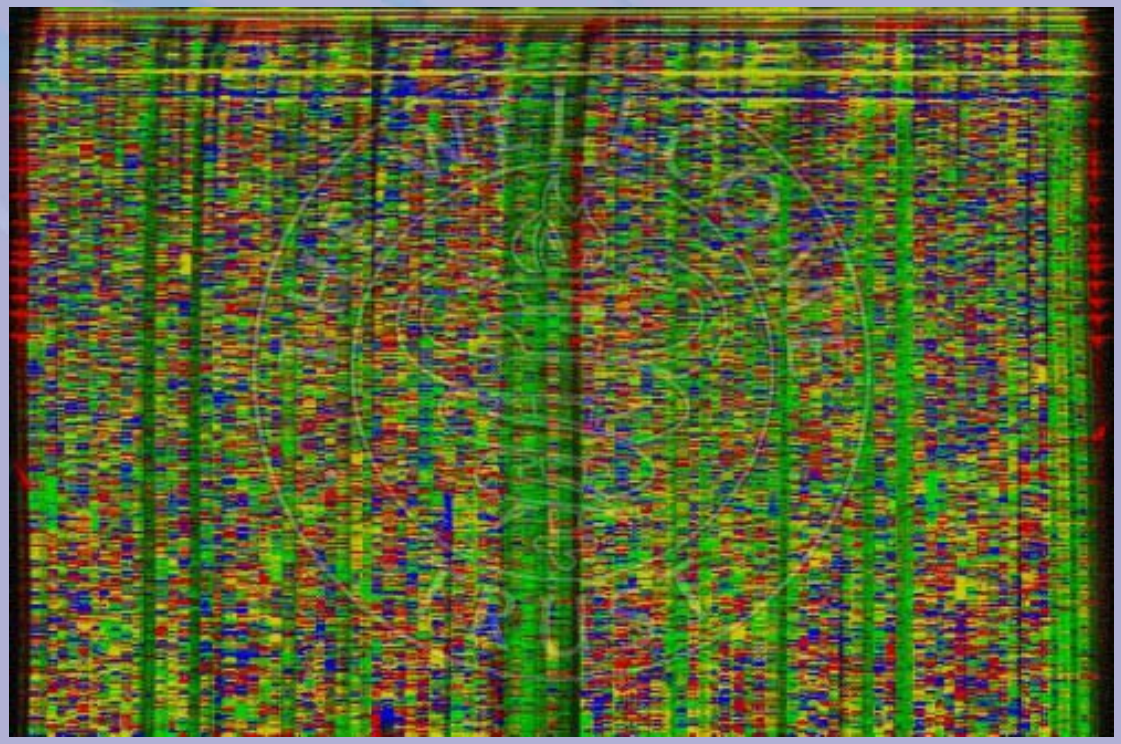
DNA Sequence



Examples of NZ Research

- Identification of genes associated with diseases eg. gastric cancer in a Maori whanau
  - development of a diagnostic test
  - identify individuals at risk of disease
- Study of relationship between genotype and behaviour (anti-social behaviour in men)
  - links to understanding of development from birth to adult

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Regulation of Genetic Research

- Ethical review of research proposals involving human participants
- Review by HRC Gene Technology Advisory Committee (GTAC)
- Review by ERMA (as appropriate)

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HRC Gene Technology Advisory Committee (GTAC)

- Standing Committee of HRC: operates under provisions of Medicines Act (1980) to recommend Director General of Health whether a clinical trial (eg. gene therapy) should proceed
- Reviews pre-clinical data, clinical trial design, safety, expertise of investigators risk management assessment
- GTAC (Chair, Associate Professor Ingrid Winship, University of Auckland) includes clinical biomedical and ethics expertise

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Population Based Genetic Databases

- Have potential to provide valuable insight into the relationship between genes, health and disease
- They are being established overseas (eg. Iceland and UK)
- Potential for both public good and commercial benefit
- Complex long term studies which are very expensive
- Involves need to link information in different databases

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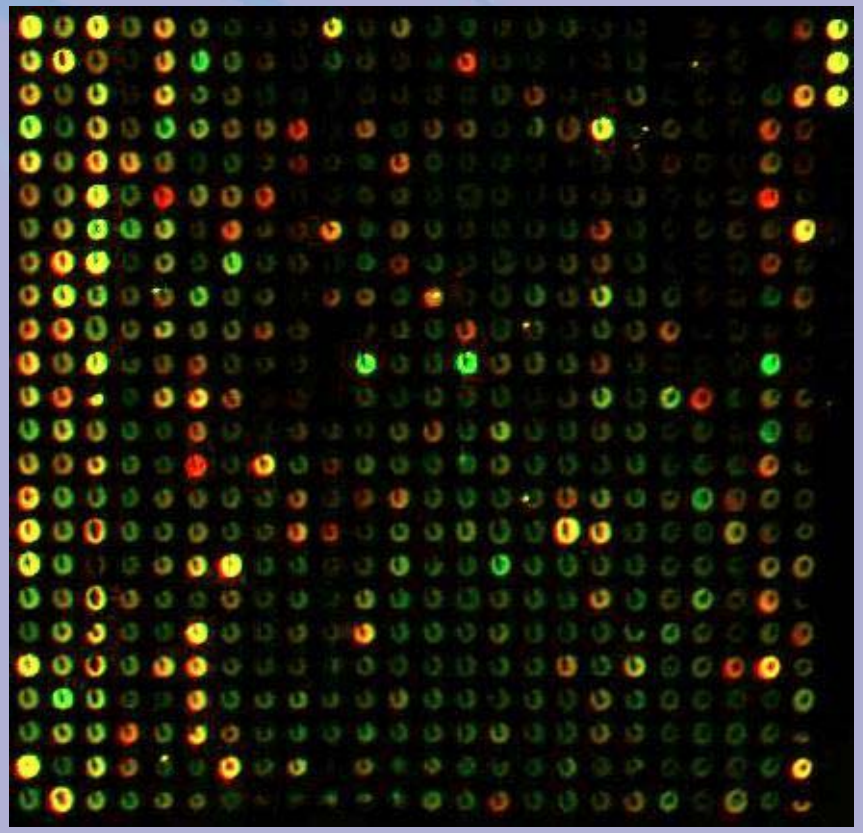
Micro-array



UK Biobank Project

- 500,000 subjects aged 45-69 years
- Aim to uncover genetic and environmental factors leading to common diseases with complex etiologies
- Consent issues: broad vs specific
- Use of general consent if anonymisation of data and samples (HGC)
- Importance of consultation with all stakeholders (including public)
- Confidentiality and commercial interests

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Genetic Studies may Raise Many Issues

- Ethical concerns
- Cultural issues
- Privacy concerns
- Potential for inappropriate use of information
- Security of information
- Public acceptability
- Legal issues
- Risks of discrimination

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New Zealand's Response to the Challenges

- Establishment of the Bioethics Council
- Development of a Biotechnology Strategy
  - effective regulation
  - community engagement
- Guidelines on ethics for genetic research
- Review of legal implications
- Responsiveness to Maori

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Conclusions

If tomorrow's challenges are to be addressed today:

- We must be proactive rather than reactive
- We must communicate and consult
- We must recognise that we are a small part of a rapidly expanding global initiative
- We must balance the potential benefits with the risks of introducing new genetic technologies

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