

8% of Australians have a rare disease

- 180,000 NSW children have a rare genetic disease
- 2,000 children referred to SCHN genetic departments annually
- 400 children diagnosed with cancer every year in NSW
- Lifelong medical and care costs
- High levels of distress for families
- Lower productivity among parents



LUMINESE ALLIANCE: A ground-breaking, innovative and translational paediatric research hub for NSW



DIAGNOSE

Functional genomics:

Identify new disease-causing genes and how to treat them



UNDERSTAND

Data:

Turn massive amounts of data into clinically relevant advice



TREAT

Precision therapy:

Novel technologies; gene therapy; new drugs; early phase clinical trials



TRANSLATE

Psychosocial:

Support patients, families and healthcare professionals



EMBED

Implementation and economic:

Health systems research to turn discoveries into care

BENEFITS FOR KIDS AND FAMILIES

- Early diagnosis
- Better treatment options
- Personalised medicine
- Access to clinical trials
- Diseases prevented
- Better health into adulthood
- Reduced burden on families

BENEFITS FOR HEALTH

- New medical discoveries for children and adults
- Reduced disease burden
- Reduced healthcare costs
- Access to "first-in-human" clinical trials in NSW
- Skilled trained workforce
- Research leadership

BENEFITS FOR NSW ECONOMY

- New STEM jobs, especially Westmead and Randwick precincts
- World-leading talent attracted to NSW
- Commercialisation and funding opportunities; intellectual property
- International collaboration
- Leveraged funding
- Alignment with NSW Government Precincts Strategy and R&D Roadmap