

## Luminesce Alliance Key Messages and Brand Guidelines

### Introduction

**Luminesce Alliance Key Messages and Brand Guidelines** are used when talking about Luminesce Alliance.

Using standard key messaging and branding builds trust and consistency across multiple partners and platforms, including partner websites and intranets, social media, newsletters, publications, presentations and all media communications.

#### Luminesce Alliance Key Messages include:

- Standard 'Boilerplate' or 'Publications' Acknowledgement - always use when mentioning Luminesce Alliance
- Key Messages – **Include one to three messages in all communications other than in academic publications.** For academic publications, you may include these key messages as appropriate.
- Testimonials – statements from directors, that may be used (with consent) in articles as appropriate
- Frequently Asked Questions and Answers (FAQs) – use as appropriate.

#### Luminesce Alliance Brand Guidelines include:

- Spelling out 'Luminesce Alliance' in full in all mass communications including publications, newsletters, social media, websites, presentations, etc.
- Adhering to the Luminesce Alliance Style Guide whenever a Luminesce Alliance logo is used, including when co-branding.
- For support with branding, access to logos, templates and the Luminesce Alliance Style Guide, please contact [info@luminesce.org.au](mailto:info@luminesce.org.au)

### Standard Acknowledgements

The NSW Health and our partner agreements stipulate that Luminesce Alliance support must always be attributed, using the boilerplate, regardless of the amount of funding or whether the funding for the research occurred in the past or present.

Luminesce Alliance Standard Acknowledgements are always used when mentioning Luminesce Alliance. To ensure the integrity of our brand, please use the wording *exactly as below*.

#### Boilerplate acknowledgement for use in all instances other than for publications

*Luminesce Alliance is a not-for-profit paediatric research joint venture between the Sydney Children's Hospitals Network, the Children's Medical Research Institute, the Children's Cancer Institute, the UNSW Sydney and The University of Sydney. It has been established with the support of the NSW Government.*

#### Including the boilerplate in social media acknowledgement

For social media posts include the term '**supported by Luminesce Alliance**' followed by a link (at the end of the post) to a website page that includes Luminesce Alliance boilerplate acknowledgement within the body of the story.

#### Publications acknowledgement \*

*The author(s) would like to acknowledge the support of Luminesce Alliance, a paediatric research not-for-profit joint venture between the Sydney Children's Hospitals Network, the Children's Medical Research Institute, the Children's Cancer Institute, the UNSW Sydney and the University of Sydney. It has been established with the support of the NSW Government.*

\*In exceptional circumstances, minor changes to publication acknowledgement will be considered before publication. Forward your request to [info@luminesce.org.au](mailto:info@luminesce.org.au)

## Key Messages

**Include one to three messages in all communications other than in academic publications.** For academic publications, include these key messages as appropriate.

1. Luminesce Alliance brings together world-leading paediatric precision medicine researchers and clinicians to find answers for children living with rare genetic diseases and cancers.
2. Luminesce Alliance paediatric precision medicine research collaboration among health precincts, medical research institutes and universities drives excellence in research discovery, more effective translation to the health system, and improved health outcomes for children with rare genetic diseases and cancers.
3. Luminesce Alliance Enabling Platforms leverage economies of scale to provide researchers and clinicians with unprecedented access to scientific resources, data, technologies and cross-discipline specialists. The Enabling Platforms allow discoveries to happen sooner, translation to the health system to happen faster, and health outcomes that are better, for children with rare genetic diseases and cancers.

## Testimonials

### **Kathryn Greiner AO, Luminesce Alliance Board Chair**

“We have a vision to change children’s medicine around the world and we are working at a scale that ensures considerable cost savings and resource sharing. That enables clinicians to drive the research agenda and for researchers to have support for the rapid clinical adoption of their work.”

### **Professor Michelle Haber AM, Children’s Cancer Institute’s Executive Director**

“Luminesce Alliance is a wonderful example of the way medical research should be done – with the best scientists and clinicians working side-by-side to improve health outcomes. We’re so pleased to be part of the Alliance and its mission — which is to ensure research is informed by clinical problems and then implemented in a way that directly improves the health of children.”

### **Professor Roger Reddel AO, Director of Children’s Medical Research Institute**

“Complex medical problems require the combined input of researchers with a wide variety of skills and expertise, and Luminesce Alliance is making it so much easier for researchers in the member organisations to align their efforts for the benefit of children and their families.”

### **Cathryn Cox PSM, Sydney Children’s Hospitals Network Chief Executive**

“As a collaboration between clinical and research organisations, Luminesce Alliance enables clinicians to drive the research agenda - bedside to benchtop — and researchers to support rapid clinical translation of their work - benchtop to bedside.”

### **Anastasia Ioannou, Luminesce Alliance Executive Director**

“Our early successes have demonstrated the value of our prototype for a multidisciplinary, collaborative approach to paediatric precision medicine.”

## Frequently Asked Questions and Answers

The purpose of a FAQ is generally to provide information on frequently asked questions or concerns.

### 1. What is precision medicine and why is it important for children?

- Precision medicine, also known as personalised medicine, offers precise assessment, diagnosis and treatment based on analysis of complex biological systems, such as through genetic or molecular profiling.
- Precision medicine has revolutionised health care in the last 20 years with the discovery of thousands of new disease genes and the exponential growth in the sequencing of cancers and rare diseases.
- Precision medicine is especially important for children, as admissions to tertiary paediatric hospitals in NSW are dominated by genetic conditions (about 40-50% are estimated to have a major genetic contributory factor) and around 15-20% of childhood cancers appear to be associated with an underlying genetic predisposition.

### 2. Why does research into the treatment of children's rare genetic diseases and cancer matter?

- At least one in 12 babies is born with a rare genetic disease. There are over 7,000 known rare genetic diseases and 75% affect children. The causes of many of these diseases remain unexplained – 30% of affected children will die before they are 5.
- Currently, rare genetic diseases impact 180,000 children in NSW alone, many of which are serious or life-threatening. There are no treatment options available for around 95% of these diseases.
- Despite medical advances, paediatric disease is still the leading cause of death in children worldwide, particularly cancer and rare diseases. Rare genetic diseases and cancers are often associated with premature death and significant disability.
- For children with Spinal Muscular Atrophy (SMA): every child affected is estimated to cost the health system \$8 million. We have shown treating such rare diseases represents a cost-saving for the health system. *Shih, S.T.F.; Keller, E.; Wiley, V.; Wong, M.; Farrar, M.A.; Chambers, G.M. Economic Evaluation of Newborn Screening for Severe Combined Immunodeficiency. Int. J. Neonatal Screen. 2022, 8, 44. <https://doi.org/10.3390/ijns8030044>*
- For children with cancer: on average, about 1000 new cases of cancer in children and young people are diagnosed annually in Australia. About 20 per cent of Australian children with cancer (three Australian children per week) will die from the disease.

### 3. How does Luminesce Alliance support paediatric precision medicine research?

- Luminesce Alliance has established five Enabling Platforms to provide the critical infrastructure to support researchers that otherwise would not be available to individual organisations due to complexity and cost.
- Luminesce Alliance drives excellence in research collaboration and partnerships among health precincts, medical research institutes and universities, Working collaboratively removes duplication of effort, pools unique resources and information, and brings together many more resources that otherwise would not be available to each organisation, to accelerate research and its translation into the health system to ultimately deliver better outcomes sooner, for children living with rare disease and cancer.

### 4. What are the Enabling Platforms?

- Luminesce Alliance's five Enabling Platforms include:
  - i. **Functional Genomics:** identifying and understanding disease-causing genes and new treatments.
  - ii. **Data:** using big data to improve detection, treatment, and outcomes.
  - iii. **Precision therapy:** delivering new drugs and novel medical technologies that will support early-phase clinical trials.

- iv. **Psychosocial:** developing world-leading best practice for psychological, emotional, social, and educational support of patients and their caregivers.
  - v. **Health systems implementation and economic research:** translating research discoveries into new models of care.
    - The Enabling Platforms provide the systems and infrastructure necessary for paediatric precision medicine. The platforms are available to support national and international research projects.
    - The platforms provide researchers and clinicians unprecedented access to scientific resources, data, technologies and cross-discipline specialists.
    - The Enabling Platforms infrastructure enables researchers to work with clinicians and other cross-functional specialists, to make discoveries as well as translate those discoveries into the health system.
    - Luminesce Alliance's Enabling Platforms draw international interest by expanding scientific opportunities, standardising best practices, and leveraging economies of scale for the implementation of precision medicine.
- 5. How do researchers gain access to the platforms?**
- Researchers may enquire directly about the platforms via [Contact – Luminesce Alliance](#). Please provide as much information as possible so we may connect you with the most appropriate person to assist you.
  - During 2024 Luminesce Alliance is calling for Expressions of Interest for researchers, clinicians and scientists to directly engage with Luminesce Alliance platforms at optimal rates. To receive updates and information about EOIs and other news [subscribe to the Luminesce Alliance 'Illuminate' monthly newsletter](#)
- 6. How can Luminesce Alliance's precision medicine research be of benefit to my child who has cancer or a rare disease?**
- Our research enhances precision therapy knowledge and aids in the creation of new treatments. However, your child's disease may lack an available precision therapy, or specific requirements may hinder their access to therapies in development or under clinical trial assessment. To explore precision therapy options tailored to your circumstance, consult with your healthcare provider for the best guidance.