

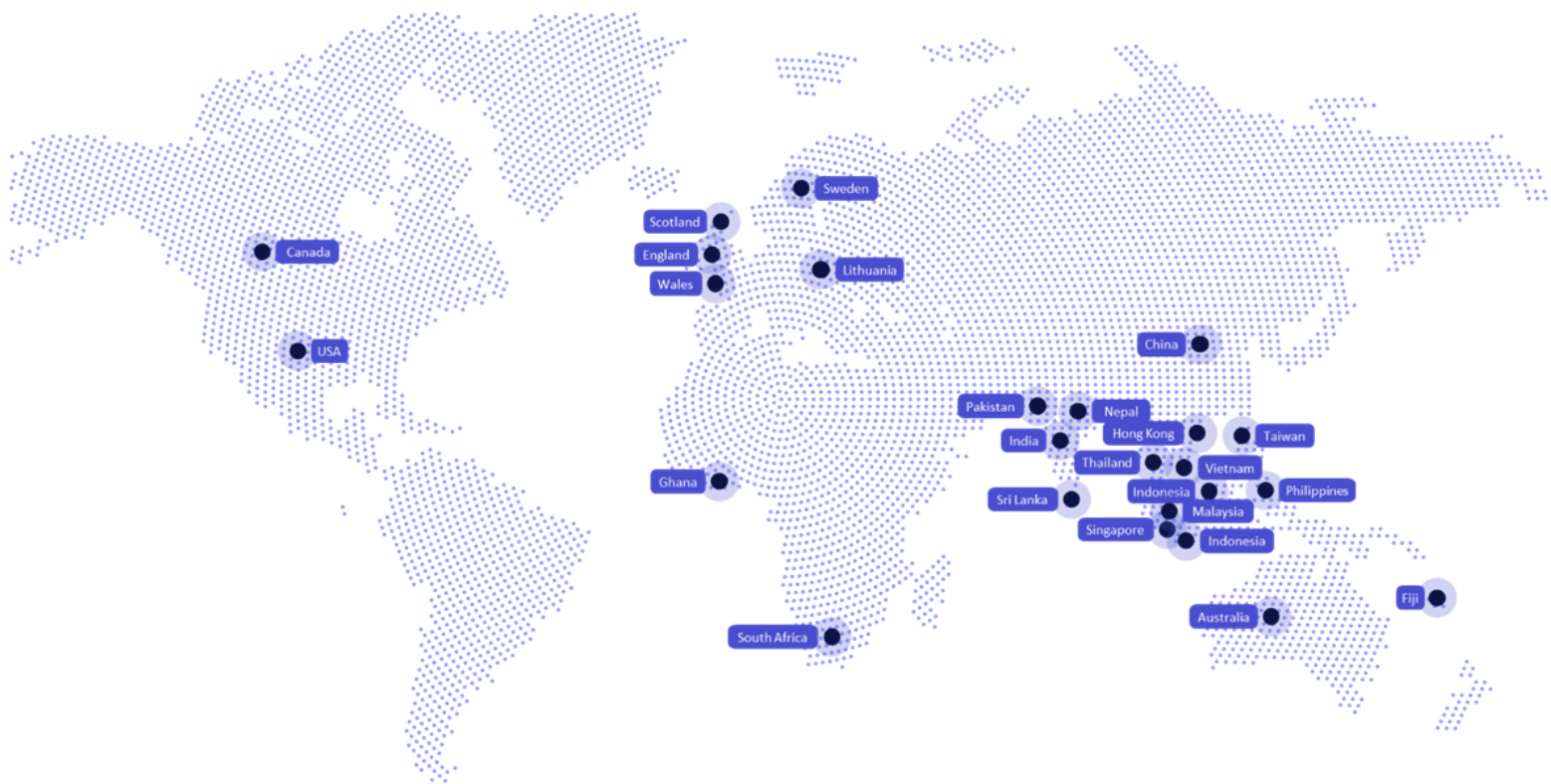


Connecting Nurses Globally

A Roundtable in Rare and Undiagnosed Diseases

9 & 10 March 2023
Curtin Singapore

Event Summary



SPONSORED
BY



Executive Summary

Rare and undiagnosed diseases (RUD) are a global health priority recognised by the United Nations (UN) Resolution on Rare Diseases and the formation of the Global Network for Rare Diseases in December 2021; a partnership between the World Health Organisation (WHO) and Rare Disease International (RDI). Affecting more than 300 million people worldwide, there are currently more than 8000 identified rare diseases, with over 70% of rare diseases starting in childhood.

The role of nurses is vital in caring for persons living with a rare or undiagnosed disease (PLWRUD) across the lifespan. Nurses are often the most accessible healthcare provider, and in some cases the only provider available. They play a critical role in delivering care, through screening, health education, care coordination, counselling, and administration of treatments and therapies. Empowered and engaged nurses can advocate for and support PLWRUD. It is therefore important for nurses to be globally connected and strategically positioned to influence local, national and global policy and advocacy platforms.

In recognition of the unique position of nurses, the Rare Care Centre, Perth Children's Hospital, Western Australia, in collaboration with Curtin University, Singapore and SingHealth Duke-NUS Genomic Medicine Centre, hosted a nursing Roundtable in Singapore in March 2023. The purpose was to invite dynamic, senior *nurses* with a focus in RUD care from various countries to co-design a RUD global nursing network and identify priorities for an education program to upskill nurses. To achieve these aims, participation was by invitation with sponsored places provided to support representation of nursing from low-and-middle income countries.

A total of 33 nurses from 25 countries across the world, representing low-middle and high-income countries from North America, Africa, Europe, Asia and Oceania attended. Eight global leaders in RUD gave keynote presentations and facilitated the Roundtable workshops. Over the two-day event, nursing attendees participated in workshops to co-design the global nursing network and outline priority areas for nursing education in RUD.

The Roundtable was successful in achieving the foundations of a global nursing network and education program with identified next steps.

We encourage all nurses to join the Global Nursing Network (GNN) by registering via the webpage: [Global Nursing Network \(gnnrd.org\)](https://gnnrd.org).

Roundtable Program

The two-day program included plenary sessions presented by internationally recognised leaders in RUD and nursing education, participant workshops and a panel consisting of four parents of children living with RUD.

Day One: The Roundtable event was opened by the Acting Australian High Commissioner to Singapore, **Ms. Angela Robinson**.

Plenary Session

- Towards a Shared Vision; a Call to Action - **Professor Gareth Baynam**, Medical Director of the Rare Care Centre in Perth, Western Australia:
 - The central role of nurses, technology innovations in RUD and the necessity for global connection to improve the care and management of PLWRUD.
- Impact of Realising the Vision - **Dr Saumya Shekhar Jamuar**, Clinical Director of SingHealth Duke-NUS Institute of Precision Medicine and Clinical Geneticist at KK Women and Children's Hospital in Singapore:
 - The BRIDGES program- Bridging Research Innovations for the Diagnosis of Genetic diseases in Singapore. The program utilises genomic technologies to directly benefit patients and improve their health outcomes, highlighting the complexity of the patient journey and the impact of obtaining a diagnosis.
- The Importance of Nurses in Rare and Undiagnosed Care; a Global Perspective - **Dr Rachel Yang**, Head of International Affairs, Chinese Alliance of Rare Diseases (CHARD):
 - The importance of collaboration at all levels of RUD care- from diagnosis, to treatment, care and research. Nurses are present at every step of the healthcare journey, they are central in delivering care across multiple settings.
 - Nurse demographics globally, and how nurse/doctor ratios vary across low-middle- and high-income countries- nurses in developing countries are comparatively scarce.

Consumer Panel

Moderated by Dr Durhane Wong-Rieger

The Roundtable invited two parents of children with RUD from Australia and two from Singapore to share their perspectives and lived experience. The panel highlighted:

- Parents are typically experts in their child's disease, which emphasises the importance of families being partners in care and truly being heard.
- Nurses are the most accessible providers of care and support in the medical setting. In the case of RUD one parent explained "walking the fine line of providing education without alienation" illustrating the delicate balance parents must manage when they often know more than a healthcare provider about their child's RUD.
- The importance of nurses upskilling parents in providing medical care for their child.

Plenary Session

- How Can Specialist Nurses be Leaders through a Global Network? - **Dr Durhane Wong-Rieger**, Chair of RDI, CEO and President of Canadian Organization of Rare Disorders (CORD) and leadership roles in other RUD organisations:
 - The proposed structure for a Rare Disease Network in Canada, describing the need for equitable access to care and pathway to diagnosis.
 - The steps towards development of a Global Network for Rare Diseases, supported by the WHO and RDI.
- A National Nursing Network for Rare Diseases- **Michelle Conway**, founder of a CRD Consulting and the previous CEO of Rare Disease Nurse Network UK:
 - The key role of nurses in providing care and support for RUD patients, discussing the commonalities and similar challenges faced by PLWRD.
 - The results of a survey of Scottish and Welsh nurses caring for PLWRD, demonstrating their gaps in knowledge, and emphasising the need for training resources for healthcare providers.

Workshop

These workshops focused on co-designing the nursing network; defining the vision, mission and objectives; and considered the logistics and features of the Network. The following were confirmed:

- VISION** Empowering nurses globally to support and improve the lives of PLWRUD
- MISSION** Building capacity of nurses through leadership, knowledge and skills in partnership with PLWRD
- OBJECTIVES**
- Connect and increase collaboration among nurses working with PLWRUD globally
 - Empower nurses as key resources to promote and implement comprehensive care for PLWRUD
 - Inform and influence the development of nursing education resources to upskill and raise awareness of RUD across the nursing workforce
 - Strategically influence local, national and global policy and advocacy platforms
 - Ensure a focus on research, clinical trials and evaluation metrics
 - Connect and share expertise with other networks to add value

Guiding principles for the Network

- Equitable access and care
- Cultural safety and responsiveness
- Partnering with patients and families

Day Two- The focus of the second day was nursing education priorities, collation of the two-day workshop data and planning for the next steps.

Plenary Session

- 'Nursing Education: Setting the Scene'- **Professor Linley Lord**, Pro Vice Chancellor and President, Curtin Singapore and **Professor Tracey Moroney**, Head of Nursing School, Curtin University:
 - Incorporating person-centred teaching into the delivery of education to facilitate the development of care and compassion whilst incorporating science and evidence-based practice.
 - The benefit of micro-credentials to upskill nurses.
 - The role of artificial intelligence and digital transformation in the health setting and how the capabilities of these technologies can be beneficial to delivery of care.
- 'Implementation of an Education Strategy for RUD'- **Associate Professor Birute Tumiene**, Vilnius University, Lithuania:
 - The existing inadequate level of rare disease knowledge and awareness among the current and future health workforce across Europe, and the need for integration of rare disease educational resources across organisations.
 - The need for an education strategy to improve the care and address the unmet needs for PLWRUD.

Workshops

Establishing priorities for a RUD education course for nurses incorporating:

- Genetics and Genomics
- Physiology and pathophysiology (RUD red flags)
- Genetic Counselling
- Mental Health first aid in RUD
- Care coordination and integrated care best practice models
- Ethics and research e.g. clinical trials

Mentorship program hosted through the Network

- Provision of clinical supervision and debriefing for nurses working with PLWRUD

Final presentation

Sue Baker, Program Director of the Rare Care Centre, Perth Children's Hospital, Western Australia presented the following:

- Summary of the outputs from the two-day workshops
- The GNN implementation strategy (developed at a global leaders meeting)
 - Quick wins for the Network to be completed within three months
 - 'Next steps' for the initial 12 months

Next Steps - Initial 12 Months

The following next steps were outlined:

- Transition of the Roundtable leadership organising committee to become the initial implementation committee
- Development of the Network strategy
- Secure a resource to drive the Network development and implementation
- Develop a business case for sustainability
- Establish a network entity with a clear governance structure
- Publish information about the Network (press statement, opinion piece, journal article)
- Leverage existing global relationships to legitimise the Network e.g. World Health Organization, Australian High Commission in Singapore
- Develop a plenary session to be included in nursing, rare disease and other relevant conferences

Quick Wins

In addition, quick wins were identified that could be achieved in the first three months:

- ✓ Provide a Network powerpoint, photos and videos, and 'next steps' action plan for attendees to present to their area/country
- ✓ Develop a GNN web landing page followed by a comprehensive website
- ✓ Establish initial Network nursing reference group
- ✓ Commence recruitment of new members (register via the webpage)
- ✓ Set a clear vision, mission and objectives of the Network
- ✓ Create schedule of meetings/activities to keep initial members engaged
- ✓ Establish a contact list and interim communication channel for attendees

Benefits of a RUD Nursing Network for PLWRUD

Ultimately the intended outcome of a GNN is to benefit PLWRUD across the world by:

- Better care and support for patients and families through increased knowledge and upskilling of nurses.
- Improving access to diagnostic pathways through earlier identification of red flags and increased screening.
- Improving clinical outcomes through increased access to clinical trials, treatment and therapies.
- Reducing stigma, isolation and discrimination through increased awareness and advocacy for PLWRUD.

“

We need to improve the care that families and people living with rare conditions experience on a daily basis - Michelle Conway

”

“

This meeting is about connection. Creating connections for families to put them in touch with the services they need - Parent, Consumer Panel.

”

Event Feedback

The event was highly evaluated with 78% of participants rating the event overall as 'Highly valuable', and 22% as 'Valuable'.

100% of participants indicated they would join the Network, and 95% would recommend to colleagues.

Comments included:

- "It was like a breath of fresh air, it was a brilliant event to participate in, was well run and amazing to be with such a breadth of experience and knowledge within the room."
- "I particularly like on the last day when all our ideas came together, formalised, giving a sense of purpose and achievement."
- "A good platform for nurses to share their experience."

Conclusion

The Roundtable event has received significant global attention and garnered the support of global leaders moving forward. Attendees expressed their gratitude and warm sentiments for the organisation, content, and delivery of the event. The Roundtable has provided the catalyst for raising awareness and educating nurses in RUD globally.

This event would not have been possible without the commitment of our sponsors who have generously donated their time, effort and funding towards the delivery of this important initiative along with the venue provided in-kind by Curtin Singapore, and support from the hosts' organising teams. In acknowledgment of this support we extend our gratitude and sincere thanks.

Visit the Global Nursing Network webpage to view the summary video of the event and access the Roundtable presentations.

If you are a nurse, please register through the webpage to join the Global Nursing Network: [Global Nursing Network \(gnnrd.org\)](http://GlobalNursingNetwork(gnnrd.org)).

