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## UNLOCKING POTENTIAL THROUGH PHILANTHROPY

**It can take up to 17 years for research to translate to clinical care – that’s an entire childhood.**

**S**ydney Children’s Hospitals Foundation CEO, Kristina Keneally, discusses how the power of philanthropy can fast-track transformative care from the bench to the bedside and change the lives of sick kids and their families sooner.

Sydney Children’s Hospitals Foundation (SCHF) exists to help provide all children with access to the best possible healthcare, whenever and wherever they need it. We are proud to be the exclusive philanthropic partner of the Sydney Children’s Hospitals Network, the largest kids’ health network in Australia, encompassing two major children’s hospitals, specialised care services and cutting-edge paediatric research.

After working in public service for 20 years – in elected roles at state and federal levels, as well as several years as a member of the press gallery at Parliament House – one of the things that excited me most about joining SCHF was the chance to support the clinicians and cutting-edge researchers at the Network.

I began my career 30 years ago in the philanthropic sector at the Society of St Vincent de Paul. I know that philanthropy is key to delivering the best possible

outcomes. By leveraging the power of philanthropy, we can aim for radical advancements in children’s health. But it means galvanising the community behind the cause.

It can take up to 17 years for research to translate to clinical care – that’s an entire childhood.

With the help of generous donors, SCHF invests in research that accelerates the ability to take crucial discoveries and turn them into innovative treatments, prevention strategies and cures to make a bigger impact on children’s health, sooner.

Through the power of philanthropy, we are fast tracking transformative care from the bench to the bedside, and back again. And with government and philanthropy working hand in hand, advancements will come faster than we ever thought possible.

A researcher recently shared with me that the job can sometimes feel like you’re standing alone in a room, surrounded by a lot of different doors. Each door represents a new treatment, theory or line of investigation. Alone, it can feel overwhelming and hopeless to explore every single door and what lies beyond.

What they said next struck me. They said that philanthropy makes it so you’re no longer alone. You now have the space, the people and the resources to open those doors and search for lifesaving, and life-changing, answers.

The researchers at SCHN are at the forefront of their fields, delivering groundbreaking research projects and

Kristina Keneally



providing the best possible care to young patients. With critical philanthropic backing, we have been able to unlock unrealised potential of outstanding researchers, support lifesaving clinical trials, explore new ideas, and provide the necessary infrastructure and environment for the Network's expert hospital teams and researchers to thrive. We are giving researchers the support they need to open new doors and make ground-breaking discoveries.

We have seen this already with the world-first clinical trials led by former SCHF-funded Fellow, Professor Michelle Farrar, Paediatric Neurologist at Sydney Children's Hospital, Randwick. Professor Farrar completed a Neurology Fellowship in 2007-09 and has since spearheaded diagnostic and treatment advances to help babies born with the devastating genetic condition, Spinal Muscular Atrophy (SMA). Until recently, the average life expectancy of a child with SMA was just nine months.

With the support of government and philanthropic funding, Professor Farrar's efforts were instrumental in creating two life-saving outcomes for babies with SMA. A new gene therapy is now listed on the Pharmaceutical Benefits Scheme (PBS), saving families hundreds of thousands of dollars each year, and NSW Health has permanently added SMA to the newborn bloodspot screening in NSW and the ACT to ensure early diagnosis. Without philanthropy, this simply would not have been possible.

**“ But research does not happen in a vacuum, and it cannot exist on project-based funding alone. To make tangible, transformative change come faster, our researchers need sufficient resources to operate. They need ongoing funds to support vital infrastructure, equipment and positions.**

SCHF funds crucial clinical trials infrastructure and key clinical trial research staff across the Network, such as clinical trial centre managers, nurses, and pharmacists. These spaces and support staff are essential for the Network's researchers to participate in high-quality clinical trials each year.

The incredible success of the SMA clinical trials is proof that by using philanthropic funds to invest in the specialists of the future, and the dedicated teams and purpose-built environments that enable their work, we can put clinical trials into practice for sick kids and their families faster than ever before.

With critical philanthropic backing and government support, we have been able to unlock unrealised potential of outstanding researchers, support lifesaving clinical trials, explore new ideas, and provide the necessary infrastructure and environment for the Network's expert hospital teams and researchers to thrive.

Philanthropy truly can transform children's health in Australia and around the globe. Where existing government and grant funding can't stretch, committed philanthropists are filling the gaps and making our good Australian hospitals great.

The SMA Newborn Screening Pilot and its economic analysis were proudly supported by Luminesce Alliance.

**Author: As CEO of Sydney Children's Hospitals Foundation (SCHF), Kristina leads the strategic direction, vision and purpose of the organisation. With a career spanning nearly 30 years across both public and not for profit sectors, Kristina has dedicated her life to making a positive impact in the lives of individuals and communities. During her time as Premier of NSW and an Australian Senator, Kristina worked several front bench portfolios including Home Affairs, Immigration, Planning, Disability Services, and Ageing. Kristina is married and the mother of two grown sons and a daughter, Caroline, who was stillborn. Kristina was Patron of Stillbirth Foundation Australia for many years and is well-known for her advocacy to reduce stillbirth in Australia.**