Professor Jonathan Carapetis, Director, speaks passionately about Telethon Kids, an Australian research institute focusing on a wide range of child health issues. He describes what attracts researchers to the organisation, and the importance of large-scale collaboration in tackling chronic diseases and other major health concerns.
Can you begin by introducing the Telethon Kids Institute and its key objectives?

While we have affiliations with universities, particularly the University of Western Australia, Telethon Kids is an independent research institution tasked with conducting critical research to benefit child health.

We were established 25 years ago in Perth, under the vision of Founding Director, Professor Fiona Stanley, who is something of an icon in this part of the world. Our aim is to provide effective child health research for Western Australia, but with an unashamed focus both nationally and globally.

The research we conduct crosses the boundaries of science, and has practical value to kids and their families. We see ourselves as having a responsibility not only to build good evidence and knowledge, and to be a strong academic organisation, but also to act as a voice for the community.

What are your current main activities and how do you ensure you meet your goals?

We are midway through a five-year strategic plan that’s centred on outcomes. Indeed, the most important statement in the whole plan is that we want to be judged on how we contribute to health and wellbeing, rather than on traditional metrics like publications and grants. Not that we don’t regard those as valuable and important, they absolutely are for our academic credentials and for assuring the quality of our work, but for the rest of the community they are meaningless.

The most important thing is that we are here to do significant work that leads to improved health. We have a broad range of activities because we aim to tackle all
child health concerns; however, our long term goal is to concentrate on a few major priority areas and do them well rather than attempting to address everything. Presently, our remit ranges from high-tech laboratory discovery research, to working in the clinic (particularly in hospitals and primary healthcare settings), understanding disease, trialling new therapies and improving those that exist.

In addition, the Institute aims to better understand how routinely collected data can help us understand disease better; we have a very strong focus on epidemiology and on using big data analysis more effectively to understand disease and track responses to new therapies. We’ve got the lab scientists bumping heads with clinicians and epidemiologists all in one big melting pot!

**The Institute’s work is grouped into four research areas. Why are these areas of particular importance?**

Telethon Kids came up with a plan to conduct great research, connect to the community, support our people and diversify our funding sources. Once the plan was cemented, we considered its implementation. We looked first at the future of research, which is about big, connected partnerships. To tackle big problems like asthma, childhood obesity or poor child development, large, diverse collaborations are required between healthcare workers, academics, service providers, community groups and governments.

In Australia, creating a blueprint for what future research institutes will look like is very important Initially, we had around 40 research groups working on different areas. Therefore, the next step was to see how they all fit together thematically, and how we could use that as a mechanism to create better connections between the researchers. From this, four big themes emerged that describe the most important areas of child health research today. The focus areas are not definitions of who we are, but rather what we do. Any researcher is expected to work across multiple areas; for example, one expanding area includes identifying the links between chronic diseases and mental health. It’s an important project that brings together two big focus areas.

**How does the organisation’s multidisciplinary approach facilitate its researchers to better tackle complex diseases and issues?**

Many targeted approaches to prevention have been tackled. We’ve already developed vaccines for many infectious diseases. There are even effective therapies for many cancers – the most common form of childhood leukaemia, for example, is an enormous success story; kids who were dying 30 years ago from this disease are largely surviving today. The issue now is that diseases are much more complex. There are still aggressive cancers that kill children, but we’re also dealing with the enormous side effects from available cancer treatments.

If we look at other big health issues (for example, complex chronic diseases), we know that the vast majority of influences leading to chronic diseases in adulthood occur right at the start of life, and in fact can even begin in previous generations. We’re now unravelling incredibly complex connections between biology, social environments and previous generations. Tackling such complicated problems requires multiple approaches, and that’s why Telethon Kids is forging large collaborations between people from different disciplines.

My work focuses on rheumatic heart disease, which affects around 40 million people worldwide – mainly in developing countries. This condition needs to be tackled in multiple ways, and there are feasible measures not being implemented that could lead to improved treatments and prevention. These require us to work at the health systems level, and also to better understand the disease so that people can take control over their own lives. Simultaneously,
we are looking at new antibiotics and vaccines for preventing the disease in the first place.

**Why does the Institute have a renewed focus on translation and discovery? What advice would you give others in the field in terms of transforming research into practice?**

Researchers have been slow in responding to what communities are saying, and can have a tendency to sit in their ivory towers. The people who provide funding for our research – generally governments, but increasingly philanthropic and private corporations – want to see much more accountability from us.

There has been some amazing progress, but it’s not enough; there is still plenty of research being conducted by individuals or small groups of people that will never see the light of day. As funding becomes increasingly more difficult to secure, people want to support research that is either going to deliver rapid results or that can at least articulate a pathway to improved health outcomes.

Telethon Kids doesn’t see this as a challenge, but an opportunity. In the future, researchers will all need to build strong connections and be able to physically document how they are making a difference – even for discoveries that might lead to new treatments 10 or 20 years down the line. It will also be important not to be overly academic and precious about who you are.

**What draws researchers to work at or collaborate with the Telethon Kids Institute?**

We speak a language that researchers, organisations and funding bodies understand. People are interested in coming to a place that encourages highly collaborative translational research. There are some scientists who prefer to stick with the older model, but I think this will become an increasingly dwindling group as researchers begin to work in a more connected way.

I’ve heard the term ‘research hotel’ used frequently: once a researcher is awarded a grant, they check into spaces or facilities and are left to their own devices. When the funding stops, they check out. We, as an organisation, have a bigger vision, and want to take responsibility for the research we conduct and be more strategic in the way we bring people together.

We are not precious about the institute itself; we are very happy to be a part of bigger collaborations. In fact, many who work at and with the Institute are from other organisations. When we hold our steering committee meetings we’ll sometimes have more than 100 people in a room talking about future research directions. Well over half of those people are from hospitals, government organisations, universities, other organisations and community groups, and they are all setting our research agendas.

It’s not all beer and skittles; there are struggles along the way. Overall, however, we are seeing some fantastic new projects being funded, and incredibly quick progress by some research groups – for example, working with Aboriginal groups to stamp out foetal alcohol spectrum disorders in some remote communities.

**How do you see the organisation developing in the future?**

We are currently in the process of physically moving. Perth is building a children’s hospital that will be a wonderful, state-of-the-art facility, and we get to be a part of its creation. The transition to the new building will happen towards the end of 2016, and it will provide a great platform to bring clinicians and researchers together.

Over five years, we hope to demonstrate how we are delivering on our vision and strategic plan. We will need to show that this model works and that we are continuing to embrace new areas of healthcare, such as precision medicine.

The Institute also aims to expand its scope internationally. We are already developing strong links in Asia and Africa, and despite being the most isolated city on Earth, we are the closest Australian major metropolitan area to these countries. This provides some enormous opportunities to tackle some important health issues, and also to draw on their expertise. My feeling is that the Institute will continue to be a great part of this community, but will also evolve to become a more relevant research organisation for major health issues and children around the world.

www.telethonkids.org.au

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**TELETHON KIDS: RESEARCH FOCUS AREAS**

**Professor Jonathan Carapetis explains the collaborative research networks that connect the Institute’s scientists with external researchers, health services and consumers**

**BRAIN & BEHAVIOUR**

This theme concerns child development: how a child is cognitively, emotionally and socially equipped for life, with the view of becoming a strong, healthy and productive adult. It also includes exploring abnormal child development linked with education, mental health issues, adolescent health and child disability.

**CHRONIC DISEASES OF CHILDHOOD**

Here, the Institute acknowledges the importance of tackling big diseases and looking for great new diagnoses, cures and prevention. Diseases such as asthma, cystic fibrosis, diabetes, cancer and rheumatic heart disease are investigated.

**EARLY ENVIRONMENT**

To better understand human interaction, Telethon Kids focuses on the life course of a human from preconception through to adulthood. This includes the developmental origins of health and disease, and external influences on health – such as nutrition, infectious diseases and vaccines, and the physical or ‘built’ environment.

**ABORIGINAL HEALTH**

Of course, the three focus points mentioned above are also critical to Aboriginal health, but due to the importance of this topic in Australia, Telethon Kids decided to dedicate a Focus Area specifically to it. The Institute is conducting work around areas such as foetal alcohol spectrum disorders, infections and vaccines, and restorative justice and mental health, to name but a few.

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