



NHMRC CRE.CKD FORUM

Improving outcomes for people with CKD



Presented to:

NHMRC CKD.CRE Forum,
RBWH Education Centre,
Edwin Tooth Auditorium

Presented by:

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Snapshot – Kidney Health Australia

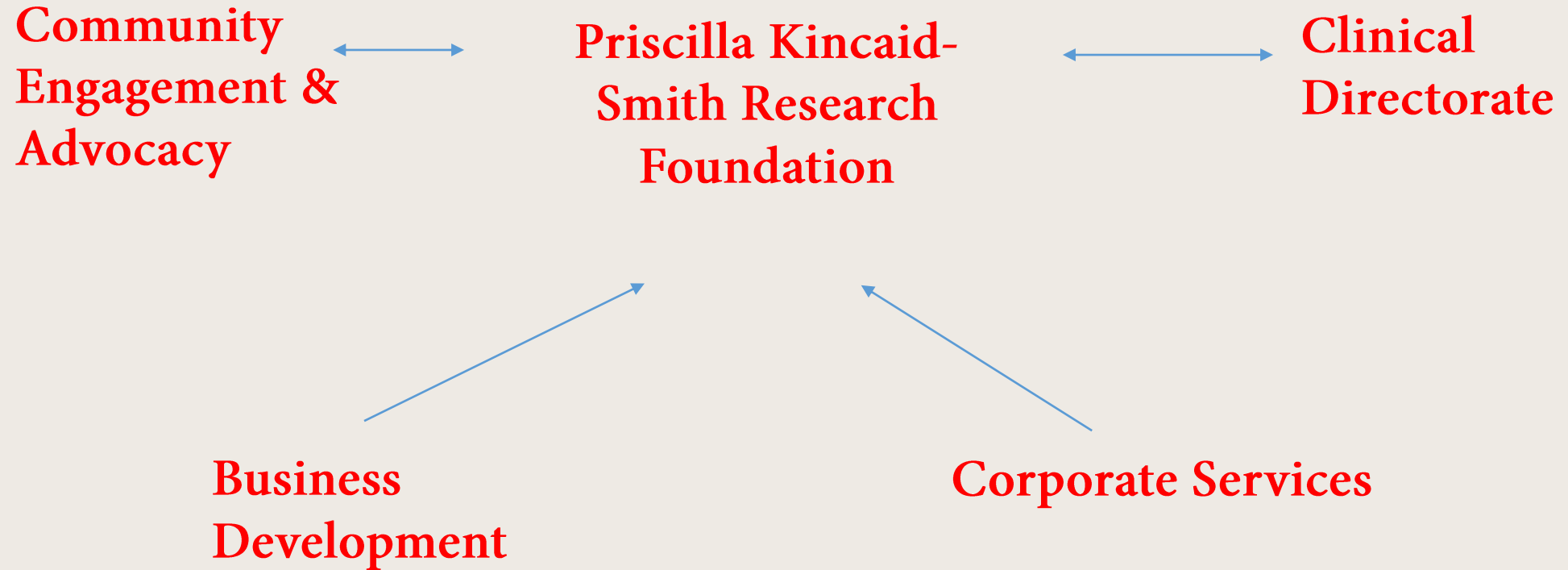
A little bit about us

Overview

- Established in 1968 by nephrologists in SA for purpose of research;
- Today – represent Australians living with kidney disease;
- Presence in WA, SA, VIC, TAS, NSW, QLD employing 79 people
- Committed to partnership and collaboration
- Independent of government funding, self funded through donations and lotteries business
- New board including MAJGEN Peter Haddad, 2 from corporate and 1 philanthropist with strong commitment to Indigenous kidney health

Structure

Focus on three main areas of practice wrapped in an indigenous overlay



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Community

- Activities in hospitals and in communities to empower, educate and combat social isolation;
- Facilitate the exchange of clinical and other kidney disease related information
- Introductions to external community services
- Examples of our activity – transplant housing, young adults program, Children's camp, volunteer management, BRKB to provide mobile dialysis at holiday destinations

Engagement

- Amplify key messages using online and offline distribution channels, patient lounge and outpatients clinics, GP clinics
- conduct events including the Kidney Kar Rally, World Kidney Day and the Kidney Health Walk which is held in cities and towns across Australia.

Clinical Directorate

- 'Brains trust' that undertakes research, produces medical content and nutrition advice
- Work experience – indigenous doctors/nurses/medical students and mentoring opportunities

Supported by Business Development and Corporate Services team

Committed to Priscilla Kincaid-Smith Foundation

How are we committed to improving outcomes for people with CKD?

Collaboration, Awareness, Advocacy and Consumer informed Activity

Community

Defn: a group of Australians with a shared experience of kidney disease

Incl: carers, families, employers, social and other networks

Offer from KHA: **subject to verification by the community

- (i) Kids camp
- (ii) Young adults program
- (iii) Volunteer program
- (iv) BRKB
- (v) Transplant Houses
- (vi) KHIS

Advocacy

Defn: authentic voice at Fed/State level, speaking for the needs of Australians affected by kidney disease as articulated by the community

Offer from KHA: **consumer informed

- (i) Transport
- (ii) NDIS inclusion
- (iii) SLOD
- (iv) On country dialysis
- (v) National renal strategy

Advised and assisted by clinical directorate

In Partnership with others

Research

Defn: Answers to questions important to consumers

Incl: partnership with RAC (C'ee of ANZSN)

Offer from KHA: facilitating consumer led participation in clinical trials and ethics advisory committees

- (i) Partnership approach
- (ii) Fully funded

Other collaborators to name a few:

CKD.CRE, BEAT CKD, Australasian Kidney Trials Network (AKTN), Australian and New Zealand Society of Nephrology (ANZSN), Transplantation Society of Australia and New Zealand (TSANZ), Renal Society of Australia (RSA)

What questions matter to someone with CKD?

1. What are the most effective ways to prevent the progression of chronic kidney disease?
2. How can we reduce the burden of kidney disease in Aboriginal and Torres Strait Islander peoples?
3. What is the most effective way of improving patient self-management (education, use of technology etc.) and does it improve outcomes?
4. What interventions can improve long term post-transplant outcomes (drugs, lifestyle)?

Collaboration – why does it matter?

KHA is committed to working with all stakeholders

1. No-one has a monopoly on resources – it takes money, skills, patience, networks and a long term commitment to combat this disease;
2. The burden of kidney disease is wide spread and getting worse -
1 in 10 Australians over the age of 18 and if you are an Indigenous Australian, the rates are much higher (1 in 3 to 1 in 5). The burden of kidney disease in Indigenous communities is particularly heavy, complex and distressing;
3. Consumers need a strong and constant voice – they vote and politicians listen
4. All of us can learn from each other and resource allocation must be seen through the needs of the consumer

KHA properties (assets) for the benefit of consumers

Kids Camp**

Young Adults Program

Research Walk

Transplant Houses

Volunteer program

Big Red Kidney Bus

** funded by the Kar Rally

Big Red Kidney Bus (BRKB)

Update since launch in October 2014

Expansion of program

- Launch into NSW in April 2017
- Feasibility study for BRKB in QLD
- Potential partnership in WA
- China and UAE

Usage statistics (partner: Monash Health and Royal North Shore Hospital)

- 567 bookings
- 11 holiday destinations
- 37% used BRKB more than once
- Visited 38 schools and 6007 students
- 188 aged 70-79, 124 aged 60-69
- 123 - Home HD
- 423 - Hosp/Sat with 21 unknown
- 219 female and 348 male
- Typical length of stay per site 6-8 weeks

