

Reflections

Healthy Skin Program Update - June 2015

**ONE
DISEASE**

Foreword

“I am delighted to share the ongoing success of One Disease in 2015. In partnership with community and local health resources we continue to pit our will against scabies. In the first instance prioritising the most severe form of the disease (crusted scabies) which is much more common than originally reported, with approximately 1/300 people suffering from it in the Top End.

In this report we introduce three new team members, provide a summary of recent achievements and share a story of Robert who is now successfully managing crusted scabies which he suffered from for years.

I’d also like to take this opportunity to also announce that [MSD](#) are partnering with us in our aim to improve Indigenous life expectancy. The three year partnership with MSD will fund two Healthy Skin Nurses to assist communities in East Arnhem and West Arnhem to identify and manage crusted scabies, as well as provide education to households with recurrent scabies.

I hope you enjoy reading this report and thank you for believing what we believe”

-Dr Sam Prince, Founder & Chairman



From left: Kenneth C. Frazier (Global CEO Merck & Co.), Dr Sam Prince, Susanne Fiedler (Managing Director MSD Australia & New Zealand).

Goals

With a greater understanding of the spectrum of disease that is scabies, our vision remains the same and our goals are clearer.



- Encourage and support patient self management as a method to eliminate crusted scabies as a public health concern in the Northern Territory.
- Develop an effective community engagement model to reduce the disease burden of scabies in two focus regions of Maningrida and Gove Peninsula.



- Encourage and support patient self-management as a method to eliminate crusted scabies as a public health concern in Australia.
- Reduce the disease burden of scabies among children in their first year of life across remote Indigenous communities in Australia.

Highlights

Active communities

- The Healthy Skin Program is active in 28 communities across the Top End of the Northern Territory.
- The activities can range from monitoring crusted scabies patients, providing education to local clinics and community on simple scabies as well as employing or up-skilling community based workers in two pilot regions – Gove Peninsula and Maningrida.



Crusted scabies

84 confirmed cases across the Top End

This is 28 additional cases since December 2014 **+28**

4x as many cases as we had identified 12 months ago

Individuals with crusted scabies (CS) are the 'super spreaders' of the disease. They often suffer in silence and shame due to the disfigurement caused by the disease and do not present to local health care providers. Therefore identifying CS patients and ensuring they receive the appropriate treatment is required for eliminating the disease. The increase in number of cases identified means we are getting closer to eliminating this disease.

One Disease is also working on creating the world's first CS Disease Registry which will greatly improve the ability of health authorities to contact-trace individuals with CS.

Aboriginal Community Based Workers

Maningrida:

- We are in the process of recruiting 2 Community Based Workers (CBWs) in Maningrida and aim to do so by the end of June 2015. They will be assisting the One Disease Healthy Skin Clinicians and Project Coordinator with household case management of CS patients and recurrent scabies households.
- In addition, they will be conducting education sessions about scabies in local languages at the *Family as First Teachers (FaFT)* early childhood centre, both with children, their parents and teachers.
- These CBWs will also assist with our social marketing initiatives such as Project Dawn where we assess community knowledge on scabies and design appropriate educational resources to build community health literacy.

Gove Peninsula:

- In Gove, we have 2 CBWs who have worked with us for a few years. Their primary role is to provide community education and assist the Healthy Skin Clinician and Project Officer with crusted and recurrent scabies management.
- They also provide healthy skin education at a variety of locations such as FaFT and households in the local language to ensure that community members understand the disease and treatment and assist with social marketing initiatives and other projects for the Healthy Skin Program.



“My brothers are glad I don’t wake them at night anymore!”

Stories from the field

Robert’s story

Crusted scabies patients suffer in silence, shame and embarrassment so they often don’t come into clinic for treatment. They hide away and for the majority of the time, they are only diagnosed in the most serious of times. Robert Munkara was no different. He was diagnosed with crusted scabies when he was taken to hospital for a heart attack. The 37 year old was rushed to Darwin hospital from Wurrumiyanga in Tiwi Islands and once his heart was stable, it was here that the doctors introduced him to Jenny Jenkins, a One Disease Healthy Skin Nurse.

“I had this for a long time, as long as I can remember. I was itchy all the time” says Robert. But it didn’t take long for Jenny to realise that Robert had crusted scabies. “I used to go to clinic and get cream, but it wouldn’t go away. The cream didn’t work”. Robert lived a very private life sitting at home for most of his life, covered up, because he didn’t want people to look at him. His 2 brothers who lived with him also suffered along with Robert as he was up most nights, itching and in pain.

Jenny wasn’t a new face to Robert though. She often visited Wurrumiyanga for skin screenings, clinic education and to check up on other crusted scabies patients in the Tiwi Islands.

“She’s from the Skin Mob. She makes us understand about the scabie bug” says Robert. But Robert never came out of the house for Jenny to find him.

“I didn’t know I had crusted scabies. When I was in Darwin, Jenny showed me pictures which helped me learn”. Jenny was one of the few regular visitors Robert had during his time at the hospital..“I didn’t want to stay but Jenny said that it would go away and wouldn’t itch. She helped me get clothes and books so I wasn’t bored”. Robert was pleased to see that within a week he was beginning to see his skin looking clearer. After one week, there was less itching and he managed to get a full night’s sleep- something we take for granted but Robert had not had for many years.

The role that Jenny played was not only diagnosing, treating and educating Robert, but also just being there with him and having a yarn. The hospital can be a scary place for any of us, we are no longer in familiar territory with family and all of a sudden surrounded by nurses and doctors with gloves & gowns conducting tests on us. For someone like Robert, who doesn’t speak much English, it was an even more traumatic experience. The role of our Healthy Skin Clinicians are therefore to also be a support system for CS patients in hospital.

After his treatment, Robert has now come back into community and after many years enjoys going out and about, proudly showing off his shiny, healthy skin. The Healthy Skin Mob still visit Robert to ensure he continues to use his medication and liaise with the clinic to ensure he is keeping well. The Wurrumiyanga clinic plays a significant role in ensuring Robert continues to look after himself and along with our mob, helps promote healthy skin.

So what’s the best part about not having crusted scabies, Robert? “My brothers are glad I don’t wake them at night anymore!”

“She’s from the Skin Mob..she makes us understand about the scabie bug”



Robert, along with Healthy Skin Clinician Jenny Jenkins.



Robert, along with Stanley, an Aboriginal Health Worker from Wurrumiyanga clinic who works closely with clinic staff to support patients such as Robert.

One Disease in the media

Over the past 6 months, One Disease has been featured in both television and print media. This exposure helps us create awareness and share positive stories.

ABC NT 7.30 report features our work in Maningrida.

Our mob spent significant time in Maningrida last year in fighting the mite with local mob. This coverage shows our team out and about in community showing what we do, the importance of skin screenings and the downstream effects of untreated scabies.

[To watch the clip, click here](#)

Sunrise features Dr Sam Prince and Janis Blums

Earlier this year, Dr Sam Prince and Janis Blums, one of our longtime supporters were featured in Channel 7's Sunrise. Sam spoke about the significance of scabies and how we are tackling the issue in the Top End, and Janis spoke about his commitment to getting rid of this disease. Together they introduced [inkforgood](#) and showed that the only thing that should get under the skin of any Australian is a tattoo, not a preventable disease like scabies.

[To watch the clip, click here](#)

Qantas

Dr Sam Prince was featured in Qantas in-flight magazine to talk about our work. The Qantas In Flight Magazine has a readership of approximately 3 million passengers. Here, he explains why we believe creating Australia's first disease registry for crusted scabies is essential to getting rid of the scabies issue.

[To read his inspirational story, click here](#)



Testimonials

See what a few of our supporters have to say about our work.



“The Jared Dunscombe Fund has chosen to support One Disease as our current fundraising project because we really believe that the Indigenous children in these communities deserve the same opportunity as all other Australians. We could see that One Disease had such a positive focus of working with these communities and educating from a grassroots level, and their success to date is evident. The passion and commitment to eliminating this terrible disease (of which many Australians are not aware) motivated us to not only support One Disease financially but also to try and help spread the word as best we can. We believe that Jared would have been just as committed to assisting One Disease in their work to ensure that these preventable diseases are eliminated within our Indigenous communities.”



“The St George Foundation is pleased to continue our support of One Disease. Their innovative and culturally sensitive approach to health education and disease elimination is making lasting impact on the lives of Indigenous children living in remote Australia, and we wish them continued success in the future”

Marianne Lacey

“As a mother, it was heartbreaking to hear that Indigenous children living in remote Australia may be at risk of a shorter life expectancy because of an easily treatable disease like scabies. This is a problem all Australians should care about, that’s why I support One Disease regularly with a percentage of profits from my business, because like them, I believe no Australian should die of a preventable disease”

Thank you

One Disease would like to acknowledge and thank our generous supporters and partners for their ongoing support of our Healthy Skin Program.



- Bite Communications
- Centre for Disease Control
- Family as First Teachers Program
- Kelly + Partners Chartered Accountants
- Malabam Health Board Aboriginal Corporation
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- Rheumatic Heart Disease Australia
- Specialist Outreach Northern Territory (SONT)
- The Northern Territory Government
- The Northern Territory Department of Education
- The Northern Territory Department of Health
- The Twelfth Window
- ThoughtWorks Australia
- Tonic
- Top End Health Services
- Zambrero

Thank you

One Disease would like to acknowledge and thank our generous donors for their investment in a healthier and happier future for all Australians.

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