

# Partnering for change

*Bi-Annual Report December 2014*



**ONE  
DISEASE**



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# Foreword

I am delighted to report on the ongoing success of One Disease in 2014. We are continuing to be the world leaders in Crusted Scabies (CS) identification and management as evidenced by our recent publication in the [Medical Journal of Australia](#).

It is also with great pleasure that I welcome [The Hon. Robert French](#) AC, Chief Justice of the High Court of Australia, as Patron of One Disease. Chief Justice French has had significant involvement in Indigenous affairs, notably serving as the first President of the Native Title Tribunal and as one of the founders of the Aboriginal Legal Service of Western Australia. Chief Justice French is a proud addition to One Disease and I am honoured to have someone of his calibre representing us - **Dr Sam Prince**



**Dr Sam Prince**



**The Hon. Robert French AC**

# Introducing the new Board of Advisors

Our Board of Advisors in the past have consisted of a number of respected experts in the medical and scientific community who were fundamental to the development of our program. They will remain part of our Scientific Advisory Board. As our Healthy Skin Program grows, we have created a Development Board consisting of highly distinguished individuals in their respective fields to assist with the next phase of our program and advocacy. Each of them contributes to our Healthy Skin Program with their wealth of expertise in health, Indigenous affairs, communications and business.



**MS CASSY LIBERMAN**

Cassy has published a series of books on inspirational Australian women. She is a director of numerous private investment companies and a philanthropist. Read more about Cassy [here](#).



**MR SAM WHITE**

Sam is the Chairman of Loan Market and Director for Ray White. He established Loan Market's HOPE programme which supports St Vincent's de Paul, OzHarvest and the Treasure House children's home in Fiji. Read more about Sam [here](#).



**DR TERENCE KWAN**

Terence is a Division Director at Macquarie Group and works with the Macquarie Group Foundation supporting causes such as Sunrise Children's Villages and ReachOut.com by Inspire Foundation. Read more about Terence [here](#)



**MR IAN HICKS AM**

Ian is the Chairman of the George Hicks Foundation and Executive Chairman of Applied International Pty Ltd. He was Chairman of the MS Society for 14 years and was made a Member of the Order of Australia (AM) in recognition for his extensive work in this field.



**MR GEOFF RASMUSSEN**

Geoff has been one of our board members for the past few years and will be moving over to the Development Board. Geoff is a co-founder and Managing Director of Azure Capital. In 2011, he was voted one of Australia's 20 Best Investment Bankers in the East Coles corporate survey.

We are also excited to introduce our new Ambassadors and an Awareness Council to assist our fundraising efforts and help spread the word about our work. [Click here](#) to find out who they are.

# Highlights

## **Identifying, managing and eliminating crusted scabies.**

Crusted scabies is the severe form of scabies which occurs when the immune system is unable to control scabies mite reproduction. A hyper-infection can develop with up to millions of scabies mites burrowing under the skin, causing disfigurement and crusting of the skin. Individuals suffer in silence and shame, receiving little ongoing care and become the core transmitters of the disease in the community. Furthermore, crusted scabies patients have been reported to have a 50% mortality rate over 5 years (Roberts et al., 2005). Efforts in this area save lives.

Click on the video below to find out more.



One Disease, along with local health care organisations work directly with CS patients and design personalised care plans for them. Over the past 6 months we have confirmed a total of 56 CS cases in the Top End. This is 37 additional cases since our last report in June 2014.

56 cases of crusted scabies confirmed in the below regions.



# Highlights

## **Understanding community opinions.**

In order to eliminate this disease from our communities, we realised the importance of identifying baseline knowledge about scabies. Once identified, we will be able to design appropriate health resources to empower community members to recognise symptoms and seek treatment early. This year, we conducted two social marketing initiatives to better understand community opinions on scabies and healthy living.

*Project Listen* was aimed at collecting opinions on health and what a healthy community means to people of all ages. We conducted this project in Yirrkala with over 10% of individuals in the community taking part. *Project Listen* was a great initiative to build relationships with community members and gain powerful insights.

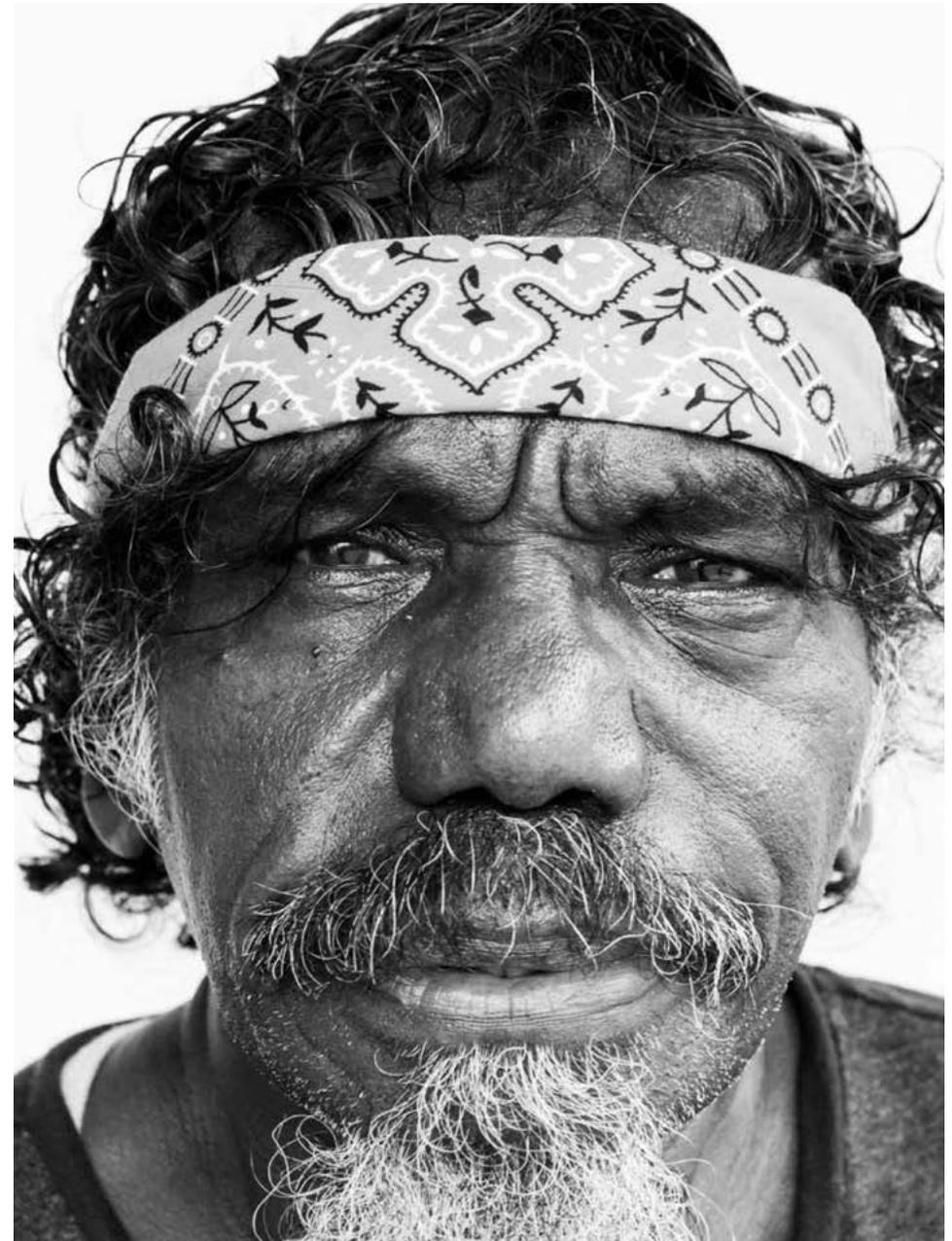
*Project Dawn* results showed a large knowledge gap in both communities about scabies (the disease itself, how you contract it and how you treat it properly). Scabies is associated with stigma and shame. People's lack of understanding of the devastating consequences of the disease is one of the reasons they rarely seek treatment early enough. *Project Dawn* was conducted in both Yirrkala and Maningrida, with over 30 focus groups. Again, we covered individuals of all ages and community groups.

### **MAIN RESULTS**

*Project Dawn* results showed a large knowledge gap in both communities about scabies. As a result, scabies is associated with stigma and the lack of understanding on downstream effects of the disease is one of the reasons why individuals did not seek treatment at early stages of the disease.

### **NEXT STEPS**

We will be working with the communities to create new resources and tools for education. Our Indigenous Community Based Workers will be up-skilled to deliver the above information in English as well as the languages spoken in community. We will also continue to provide resources to local clinics to up-skill clinical staff and assist with patient education.



Djuwalpi Marika, Yirrkala Elder

Some examples of Project Listen photos and community opinions.



Sasha Mununggurr, Yirrkala

The good thing I like in this Community  
is I grew up here Went to School here  
Finish my Year 12. (I miss School days)  
~~The best I don't like is~~  
The most thing in my life)  
But now I'm happy to be With  
My family & my Baby Girl Loretta.  
As I see in this Community  
lots of Young kids getting sick  
Which is I don't like my baby  
to get sick and end up in  
hospital.



Grace Bawu Gurruwiwi, Yirrkala

Careful for scabies and keep  
it clean. I don't like kids  
sniffing petrol. We should look  
after this Community.

A healthy Community is strong,  
everyone helping each other.

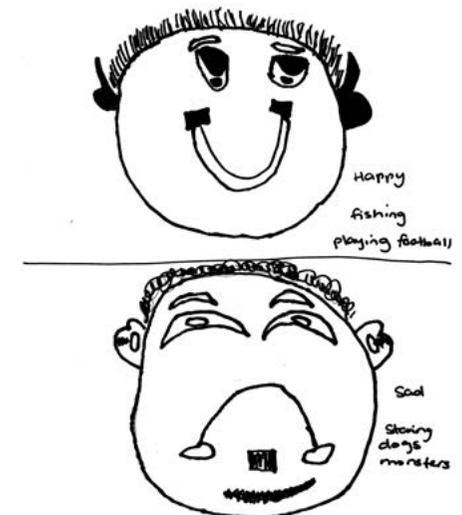


Merrikiyawuy Ganambarr-Stubbs, Yirrkala

HEALTHY COMM.  
MEAN.  
\*SUPPORTING THEIR CHILDREN  
IN ANYTHING GOOD THEY  
WANT TO DO.  
\*GOOD MANNERS  
\*SMILES & LAUGHTER  
WHEREVER YOU GO.  
\*SEEING FAMILIES DOING  
SOMETHING TOGETHER  
\*HEALTHY SMILEY  
FACES.



Jamie Yunupingu, Yirrkala



# Stories from the field

## ***My family's battle with scabies- by Adam Close***

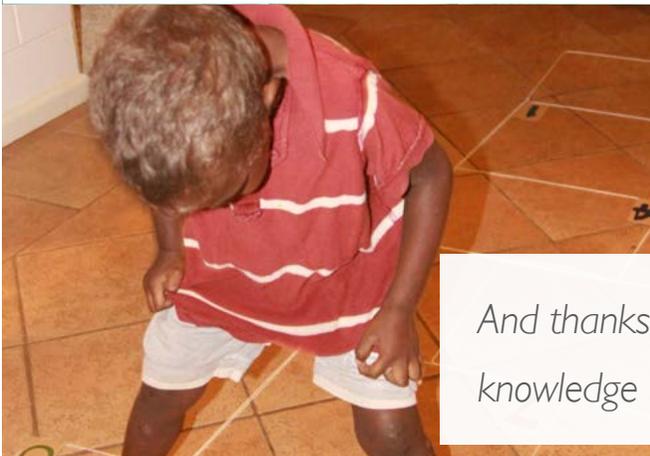


In December 2010 I began working for Kentish Lifelong Learning and Care, a family day care scheme that runs a program called Absolutely Top Care. It is through Absolutely Top Care that my family (which at that time consisted of myself, my wife and her two children) grew by 3 more - a 6 year old boy, 4 year old girl and 2 year old boy. These children came to us in need of a safe home as they displayed some behavioural and medical issues. One such issue was scabies, which we were informed by the Department of Children and Families (DCF) that the children had suffered from in the past and that it was treated. I knew little about scabies at that time and when the children arrived their skin looked clean and healthy.

Four years passed and within those years there was a lot of change, but one thing that was a constant presence was scabies. A week after the children joined us I noticed the oldest of the children had a crusty white build up on his scalp. Concerned that it was scabies I took him to the local clinic for Indigenous children. The doctor diagnosed Tinea Capitis, we were given some medicated shampoo and away we went relieved it wasn't scabies. However, after using the medicated shampoo for several weeks there was no change to the white crust, and we noticed that the other children in the house had developed tiny itchy lumps. While it was quite obvious that we were facing a case of simple scabies, suspicion was growing about this persistent crust. So it was time to do our own research. My wife visited Doctor Google and it didn't take long to find that the white crust we were seeing was very similar to what Doctor Google described as crusted or Norwegian scabies. She also discovered that crusted scabies is sometimes misdiagnosed as a fungal infection. While not wanting to make diagnoses from Google we returned this time to see a Paediatrician. It was confirmed that the children had simple scabies, but the white crust needed more investigation.

For the next three and a half years we battled scabies with creams and lotions, but it just wouldn't clear up completely.

*Everyone in the house was infected. Visitors would come and go; we had no choice but to warn them not to hug the children as you might end up with scabies.*



Despite all our efforts, and at times thinking we had got on top of it, the scabies would always return. The white crust would spread from the scalp to the ears and eyebrows, to between fingers and around genitals. You can only imagine how this would affect a young boy.

At the beginning of this year we had an appointment to see a dermatologist. Again it was confirmed as scabies and a fungal infection, but this was the first time a course of ivermectin was prescribed. We left that appointment with a sense of hope and optimism that finally we will get rid of this once and for all. However it didn't go away.

Over the years we managed the scabies with creams and lotions, and sometimes medications but we just could not break the curse of this horrible little mite. I lost faith that anything was going to stop this bug and resigned myself to the fact that we will just have to live with it and manage it as best we can.

Around July this year, I got a call from a nurse called Leonie, from an organisation called One Disease. I had never heard of One Disease before this. Leonie explained that she was made aware of the child's case and noticed that there were some issues with the prescribed treatment. I must admit I was apprehensive about her visit, as I was convinced that I would be told again that the children have scabies and get told to keep doing what we were doing. However, Leonie took one look at the oldest child (now 10) and without hesitation said "he has crusted scabies and needs to be hospitalised." With surprise and a sense of overwhelming relief I said "what.... really.... when? Now?" Leonie checked the other children and suggested that the three siblings should all be hospitalised. Three and a half years on, after visiting Doctor Google and many other doctors in-between, finally some real action was being taken thanks to Leonie and One Disease.

The younger two of the siblings spent 5 days in an isolated room being thoroughly treated for simple scabies, while the oldest child was comprehensively treated for crusted scabies for almost two weeks. Meanwhile I was able to treat everyone at home and treat the home itself, something I hadn't been able to do before the children were in hospital. I took all of the children's clothes and bedding and hung them in the sun to kill those nasty mites. For a while our back yard looked like a Chinese laundry.

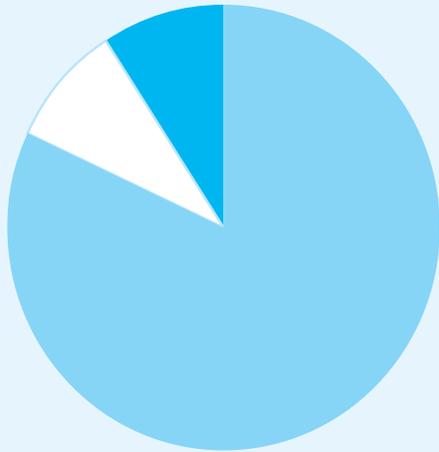
It has been 6 months since the children were treated in hospital and we have not seen any white crusts since. Without the intervention of Leonie and One Disease, our family would still be itching and scratching, fighting this mite. But now, thanks to Leonie and One Disease, I don't have to warn friends and family not to hug the children.

*And thanks to Leonie and One Disease I can give the children a hug good night, safe in the knowledge that scabies has gone, and so too, has the risk of serious long term health issues.*

Adam Close

# Where your dollar goes

## 82c OF YOUR DOLLAR GOES DIRECTLY TO THE FIELD



■ FIELD 82% ■ ADMIN 9% ■ DEVELOPMENT 9%

We know you want as much of the dollar you donate to reach the cause. That's why One Disease ensures 82c of every dollar donated goes directly to the field. With only 9c of every dollar donated going towards admin and 9c towards development costs, One Disease is in one of the lowest percentile in Australia.

**FIELD:** Working in remote communities can be expensive work. Our field costs include transport and employment costs of remote medical staff, education and employment of Indigenous Community Workers and education materials to assist in our disease elimination campaign.

**ADMIN:** These funds cover the day to day running costs to keep the lights on. No frills, just the essentials.

**DEVELOPMENT:** We spend our dollars wisely when it comes to fundraising and marketing, never investing in paid mainstream advertising or outsourcing to third-party fundraisers. All development campaigns are cost effective initiatives to gain long-term supporters to help us continue our work.

# What your dollar could do



\$16 is the price of a tube of Lyclear, the medicated cream which effectively treats scabies and protects from further presentations for up to one month.



\$100 will screen, treat and protect an Indigenous child under the age of 5 years from scabies for one year. This reduces the long term risk of developing rheumatic heart disease and kidney failure.



\$250 will cover the costs to provide an in-home scabies education session and scabies skin screening.



\$500 will provide a remote school or early childhood clinic with skin health education session and scabies skin screening.

# Thank you

*Thank you to our generous and loyal donors who collectively gave \$1.4m in the 2014 financial year.*

*These much needed funds will leave a lasting legacy on the health of our Indigenous Australians.*



**ONE  
DISEASE**  
BELIEVE. CONNECT. INSPIRE

