

A woman with her hair in a bun is holding a baby in front of a bamboo wall. The woman is looking to the left. The baby is looking down and has its hand near its mouth. The background is a wall made of vertical bamboo stalks.

ONE DISEASE

BELIEVE. CONNECT. INSPIRE

Annual Report
2015/2016

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Reflections On 2015

2015 was a significant year for our mob. We made the critical decision to focus our efforts solely on Crusted Scabies (CS).

When we arrived in the NT back in 2011, we knew very little about CS. Researchers hypothesised that CS was a rare disease where only 1 in 10,000 people may suffer from it.

Today, our data suggests that this number is much higher, a staggering 1 in 409 Indigenous people in the NT suffer from CS. They are often isolated in community and suffer in shame and silence with little ongoing care.

Furthermore, if untreated, they have a 50% mortality rate within 5 years, adding to the already wide life expectancy gap between Indigenous and non-Indigenous people in our country. People with CS can be the core transmitters of scabies in community so the impact of the disease is beyond the individual with CS. In remote communities that experience overcrowding, someone suffering from CS could have up to 20 people living in the same house, which puts many people at risk of scabies. If untreated, repeat scabies episodes and infections can lead to heart and kidney problems and ultimately premature death.

Now with a greater understanding of CS, we feel compelled to focus on those who need us the most. In the last four years we laid down foundations of the program where we worked on; writing national guidelines for CS, the development of our Healthy Skin Program, publishing our pilot program's success in the Medical Journal of Australia and establishing the world's first CS Register, currently with 91 patients. This groundwork has now brought us to the next phase of our program: expanding our efforts towards CS elimination.

At One Disease, our overall ambition is to make ourselves redundant. Our strategy is to promote ownership and understanding of CS so local clinics and patients themselves can manage the disease in the future. We believe this is the only way to create sustainable health outcomes; Allowing Indigenous health to remain in the hands of Indigenous people.

On behalf of our mob, I'd like to thank you all for your ongoing support of our program, thank you for walking alongside us in this journey and the evolution of our program, and most importantly, thank you for believing in what we believe in - that no Australian should die of a preventable disease.



Michele Bray | CEO



The Experts That Guide Us

Our Board of Advisors, Patron and Steering Committee are a group of highly distinguished experts in their fields who volunteer their time to guide us.

Our Board of Advisors



Dr Sam Prince, Founder & Director

Dr Sam Prince is a humanitarian, philanthropist, entrepreneur and medical doctor. He was awarded 'Young Australian of the Year, ACT' in 2012, in recognition for his work at One Disease. He is currently one of the 14 members in the InnovationXchange program, headed by The Hon Julie Bishop MP.



Professor Hugh Taylor

Hugh's research into the causes and prevention of blindness has led to him working with Fred Hollows, as well as 13 years spent with the John Hopkins University. His current focus is on Indigenous eye health and the elimination of Trachoma.



Professor Jonathan Carapetis

As Director of the Telethon Institute for Child Health Research, Jonathan's work has revealed a link between Strep A skin infections and the potentially fatal rheumatic heart disease.



Professor Frank Bowden

Frank is an infectious disease and sexual health physician. He is the former Director of the National Committee supervising the elimination of Donovanosis from Australia, and is continuing research into the control of infectious diseases through public health principles.



Dr Terence Kwan

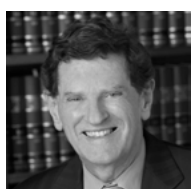
Terence is a Division Director at Macquarie Group and works with the Macquarie Group Foundation supporting causes such as Sunrise Children's Villages and ReachOut.com by Inspire Foundation.



Professor Brian Schmidt

Brian is the Vice Chancellor of The Australian National University. He formed the High-Z SN search team who won Science Magazine's 'Breakthrough of the Year' in 1998. He has won a Nobel Prize for his groundbreaking research on supernovae and the expansion of the universe.

Our Patron



Hon. Chief Justice Robert French AC

Chief Justice French has had significant involvement in Indigenous affairs, notably serving as the first President of the Native Title Tribunal. He was one of the founders of the Aboriginal Legal Service of Western Australia and served as Inaugural Chairman.



Our Steering Committee

Professor Bart Currie – Royal Darwin Hospital, Menzies School of Health Research

Dr Vicki Krause – Northern Territory Centre for Disease Control

Professor Christine Connors – Top End Health Services

Dr Lucas De Toca – Miwatj Health Aboriginal Corporation

Eddie Mulholland – Miwatj Health Aboriginal Corporation

Ray Matthews – Malabam Health Board Aboriginal Corporation


Rhonda Powell – Northern Territory Department of Health

Why Crusted Scabies?

Crusted Scabies (CS) is a highly contagious and chronic form of the skin disease, scabies. People with CS become engulfed with millions of scabies mites because their body is unable to launch an immune response to control mite replication. The result is thick, rotting flesh like crusts that build up on the surface of the skin, similar in appearance to the ancient disease leprosy. Due to the disfigurement, people with CS often suffer in silence and shame and rarely present themselves to health services.

Currently **1 in 409** Indigenous people in the NT suffer from this disease. If untreated they can have a **50%** mortality rate over 5 years.





Early diagnosis and treatment is important not only for the individual suffering from CS but also because of the wider impact this disease has on the entire community. Close contact with an individual with CS increases the risk of being infected with scabies.

7 out of 10 Indigenous babies suffer from scabies at least once before their first birthday. If left untreated, scabies can lead to heart and kidney failure and ultimately premature death.

In remote Indigenous communities that experience overcrowding, someone suffering from CS could have **up to 20 people** living in the same house.

Personal Stories

This is just a handful of people whose lives have been transformed by your support.

A man named Stephen is sitting in a black motorized wheelchair on a dirt path. He is wearing a dark blue t-shirt and black pants with white stripes on the side. He is holding a white envelope or document in his lap. The background shows a grassy area, palm trees, and a body of water under a clear sky.

Stephen

"When I first experienced it, my wife and kids had a hard time cleaning me up. It kept staying in my body. I tried everything; I just had to live with it. Im very happy that the One Disease mob is here helping the community"

A close-up portrait of a man named Wapit. He has dark, curly hair and is looking directly at the camera with a slight smile. He is wearing a light-colored shirt with thin blue and orange stripes. The background is a blurred green wall.

Wapit

"It was challenging..you're alone.. nobody will sit with you, nobody will have a chat with you. But then One Disease came and kept me clean. They told me 'hey your skin is normal now. You've got no scabies' it was good!"



Adam

"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. But now, thanks to One Disease, I don't have to warn friends and family not to hug my children, and thanks to One Disease, I can give the children a hug goodnight, safe in the knowledge that scabies has gone, and so too, has the risk of serious long term health issues"



Robert

"My brothers are glad I don't wake them up at night in pain anymore!"

Healthy Skin Program Summary

The One Disease Crusted Scabies (CS) elimination campaign is known in community as the Healthy Skin Program. Our team of flying nurses travel to remote corners of Australia and are known as the Healthy Skin Mob.



We aim to eliminate Crusted Scabies as a public health concern through patient self-management.



**Across
Northern
Territory**

By the end of 2018



**In
Australia**

By the end of 2022

We will achieve these goals through education and empowerment of Indigenous Australians who are affected by this disease and by empowering them to manage their own condition.

The Strategic pillars of our Healthy Skin Program are:



Partnership

Develop and manage ongoing relationships with community elders and clinic staff to collaborate to gain a sense of ownership



Treatment

Identify, educate and manage confirmed CS patients in partnership with family and local clinics to minimise re-infestation



Elimination

Remote surveillance of CS patients and their families in partnership with local health resources.



Working In Remote Indigenous Communities



If you haven't set foot in a remote community, we want to bring to life the places in which we work.

Our mob has been working in remote Indigenous communities for the past few years. Over that time, we have gained further understanding into working collaboratively and respectfully with community members. Every day in community is a learning experience for us.

Indigenous Australians are the oldest living culture in the world, with roots going back 60,000 years.

The experiences, challenges and learnings over the past few years have aided the development of our vision moving forward. We will continue to share stories, understandings and challenges so we can continue this journey together to eliminate CS from NT and Australia.

If you want to be the first to hear about future walks, email contact@onedisease.org



Life In Community Through The Eyes Of One Of Our Supporters: *Nicola Richards*

In November 2015, One Disease was accompanied by two of our supporters on a trip to East Arnhem Land. This trip, appropriately called the 'Walkabout', was aimed to give our supporters a first hand experience of life in community.

Nicola Richards is the Director of Commercial Operations at MSD Australia. MSD Australia & their global counterpart Merck Global are one of our supporters and donors. The following is a personal insight into Nicolas thoughts and experiences while visiting community.

Late last year, I joined One Disease on an educational trip to Arnhem Land for 5 days. I was filled with excitement and trepidation, as the opportunity to visit a community is something that not many Aussies get to experience. I felt very privileged. I was not quite sure what to expect or how I might be affected.

Once we arrived up north, we all piled into an air conditioned 4WD driven by Randy – although it was hot and humid on our first day, it was in fact hotter back in Sydney (42°C!).

Our drive was long but fascinating. The colour of the earth varied from red to white to black. We had a number of educational stops. We learned that the purple flower indicated it was shark and stingray fishing season and the bush medicine "Gatorade" root would, I was assured, make me run for days. We also learned about their connection to the land – they don't own the land, the land owns them.

All of a sudden we came over a crest and the sight of the water was amazing after 2 hours of driving through red dirt and sand. As we watched "Mr Percival" fly over, Randy saw some fish. Out comes his traditional handmade spear and whammy it's fish for dinner! He was so elegant in the way he would stand to fish: he would stand on one leg and throw his spear – I wouldn't have imagined it was really possible to do this, but I discovered he was very efficient after he delivered 5 sting rays the next day as our "delicacy" to share. In retrospect only I might have been enough but more on that later!

What do you do in Bawaka "homeland"? Jobs, sleep, lots of tea, some more jobs and more sleep! Put simply it is too hot to do much other than sleep for a large part of the day or stare into the spectacular croc-filled blue water.





We made pandanas string that we hand-dyed in red and yellow from root that we had gathered from the land. We cooked, had fresh oysters straight from the rock and prepared stingray for dinner.

We learnt about the very complex Aboriginal social structure and the fact that most locals can speak over 30 dialects, making English their 31st language. This simple fact has a profound impact on how we communicate. One misinterpretation of an English phrase can lead to another, and another, resulting in two worlds that struggle to understand each other!

I reflected on the health challenges our industry often talks about trying to solve. How does a person stay compliant with medication when they may not know where they will sleep from one night to the next? If they leave anything at one home it's a 4 hour round trip; they often have 2 or 3 homes, so where can the health care worker find them? When we refer to "community health care worker" more often than not they have limited health qualifications – how can we equip them with material they can easily understand?

As I sat on the plane on the way home after 4 days that were almost indescribable, I thought I would be physically exhausted. But I found I was far more mentally exhausted than I could have imagined. My mind was in overdrive trying to work through the maze of challenges that needed to be addressed to ensure that people can find their place in a modern world that, although had been forced upon them, is here to stay.

We are aiming to facilitate 2-3 Walkabouts per year. If you want to be the first to hear about future walks, email contact@onedisease.org



Healthy Skin Program: Wins This Year

Crusted Scabies Management

The Patient Register Continues To Grow



Since creating the Crusted Scabies Register (CSR) in 2013, we have added **91** confirmed cases across 28 communities in the NT. Over the past 12 months we have seen a **17%** increase in the number of confirmed CS patients on the register.

An increase in the number of confirmed CS patients is positive because identification of people suffering from this condition is the crucial first step in empowering them to manage their condition.

Professor Frank Bowden and Professor Hugh Taylor, members of our Advisory Board, highlighted the importance of One Disease creating the worlds first CSR. Such a Register has been a key component in disease surveillance of smallpox, HIV and rheumatic heart disease.

The next step for us is to shift this patient Register to a more dynamic patient database. Where once CS patients have been identified, we can track whether their treatment has been successful and track the management of this chronic condition over time (in collaboration with local health clinics in community).

Completed Full Audit Of The Crusted Scabies Register

Identification and treatment of CS patients are two of the first steps towards elimination. Consistent ongoing care is the next critical step that we take in partnership with local health clinics in community and the patient themselves.

Over the past 6 months our Community Nurses have performed a full audit of the 91 patients to assess the status of their ongoing care. As the prevalence of CS has only recently been confirmed as more common (1/409 Indigenous people in the NT) there is limited understanding and awareness of the condition, including; how to identify, treat and manage the chronic condition. Our audit found that there is much work for One Disease to do to educate local health clinics on how to consistently manage and record the management of CS in electronic patient records (not unlike the chronic management of a condition such as diabetes).

The next steps for us are to:

- Provide regular education sessions for local health clinics about CS (identification, treatment and chronic management) and how to record it in electronic patient records.
- Work with local health clinics to confirm consistent chronic care plans for the existing 91 CS patients.
- Develop an electronic chronic care plan for CS and work with industry stakeholders to implement in the electronic patient record systems used in the NT.



Crusted Scabies Has Been Confirmed as a Notifiable Disease

One Disease's end game is to make ourselves redundant. To do this we need to develop and implement system wide change to promote the management of this chronic condition that was previously considered a rare disease.

A significant step in this direction has been the confirmation of CS as a notifiable disease in the NT, as you can see in Table 1. The Centre for Disease Control has recognised the need for the health industry to action CS similarly to other contagious diseases such as HIV, Measles etc.

Notifiable diseases to be reported in the NT			CDC Darwin (08) 8922 8044 CDC Alice Springs (08) 8951 7540 CDC Tennant Creek (08) 8962 4259 CDC Katherine (08) 8973 9049 CDC Nhulunbuy (08) 8987 0357				
AIDS	D	Donovanosis (granuloma inguinale)	D L	Japanese encephalitis	D L ☎	Ross River virus infection	L
Acute post-streptococcal glomerulonephritis	D ☎	Food or water borne disease in 2 or more related cases	D ☎	Kunjin virus infection	D L ☎	Rotavirus infection	L
Adverse vaccine reaction	D	Gastroenteritis involving 1 or more related cases in an institution or food handler	D ☎	Legionellosis	L ☎	Rubella	D L
Amoebiasis	L	Gonococcal conjunctivitis	D L ☎	Leprosy	D L	Salmonellosis	L
Anthrax	D L ☎	Gonococcal infection	L ☎	Leptospirosis	L	Scabies (crusted)	L
Arbovirus infection - not otherwise specified	L	Gonococcal neonatal ophthalmia	L ☎	Listeriosis	L	Severe acute respiratory syndrome (SARS)	D L ☎
Australian bat lyssavirus	D L ☎	Group A streptococcal infection (invasive)	L	Lymphogranuloma venereum	D L	Shiga-like toxin (verocytotoxin) producing E coli infection	L ☎
Avian influenza	D L ☎	Haemolytic uraemic syndrome	D ☎	Lyssavirus - not otherwise specified	D L ☎	Shigellosis	L
Barmah Forest virus infection	L	<i>Haemophilus influenzae</i> - non-type b (invasive)	L	Malaria	D L ☎	Smallpox	D L ☎
Botulism	D L ☎	- type b (invasive)	D L ☎	Measles	D L ☎	Strongyloidiasis (extraintestinal)	L
Brucellosis	L	Hendra virus infection	D L ☎	Melioidosis	L	Syphilis	D L
Campylobacteriosis	L	Hepatitis A	L ☎	Meningococcal infection	D L ☎	Tetanus	D L
Chancroid	D L ☎	Hepatitis B	D L	Middle East respiratory syndrome (MERS)	D L ☎	Trichomoniasis	L
Chickenpox	D L	Hepatitis C	D L	Mumps	D L	Tuberculosis	D L ☎
Chikungunya virus infection	D L ☎	Hepatitis D	L	Murray Valley encephalitis	D L ☎	Tularaemia	D L ☎
Chlamydial conjunctivitis	L	Hepatitis E	L ☎	Non-tuberculous mycobacterial disease	D L	Typhoid (including paratyphoid)	D L ☎
Chlamydial genital infection	L	Hepatitis not otherwise specified	D	Ornithosis	L	Typhus (all forms)	D L
Cholera	D L ☎	HIV	L	Pertussis	D L ☎	Varicella infection unspecified	D L
Ciguatera fish poisoning	D ☎	HTLV1*	L	Plague	D L ☎	Vibrio disease (invasive)	D L ☎
Congenital rubella infection	D	Hydatid infection	L	Pneumococcal disease (invasive)	L	Vibrio food poisoning	L ☎
Congenital syphilis	D	Influenza	L	Poliovirus infection	D L ☎	Viral haemorrhagic fevers	D L ☎
Creutzfeldt-Jakob disease	D			Q Fever	L	Yellow fever	D L ☎
Cryptosporidiosis	L			Rabies	D L ☎	Zoster	D L
Dengue virus infection	D L ☎			Rheumatic fever	D		
Diphtheria	D L ☎						

D Notifiable by doctors
 L Notifiable by laboratories
 ☎ Urgent if suspected to have been acquired in the NT

☎ Urgent for any penicillin resistant isolate
 ☎ Please notify CDC urgently by phone.
 ☎ Doctors please notify on clinical suspicion (while awaiting laboratory confirmation)

HTLV1* - Adult T cell leukaemia/lymphoma and tropical spastic paraparesis notifiable by doctors



Table 1: Notifiable Diseases in the NT, February 2016. Taken from www.health.nt.gov.au

Notifiability is a formal way of partnering with existing health services to manage a chronic condition. It reinforces the importance of treating CS as a serious health condition that must be notified to appropriate health services immediately and treated accordingly to avoid any possible outbreaks. The next steps for us are to work on the process with NT Department of Health to receive patient details and include them on the register. We will then be able to use this information to support community healthcare workers in community to manage existing and new patients.

These are system wide changes that One Disease and other key stakeholders have facilitated, with the overall aim being that local health clinics are able to manage CS without our mob moving forward.





Testimonials

Crusted Scabies is not a well-known disease, but one that has a myriad of associated health and social implications for those suffering from it and their families.

On meeting Dr Sam Prince in 2012, I was impressed with his commitment to eliminating this significant health issue and the sensible and sensitive way in which he has approached the task and engaged with remote communities in Arnhem Land.

One Disease is achieving significant results in their efforts to identify, treat and control the disease while at the same time educating indigenous people about the prevention of Crusted Scabies.

For these reasons we have been proudly supporting the work of One Disease since that first meeting.

Mitty Williams
The Kimberley Foundation
Donor

The Menzies School of Health Research is very supportive of the work of One Disease. We have an active research program on the Healthy Skin issues in remote Indigenous Communities and we collaborate with One Disease on prioritising the work for the future. Most important is the framework that One Disease has developed for the ongoing support for patients who have been diagnosed with Crusted Scabies. This is an area that has been difficult to address through the routine health services. The focused work of One Disease around family groups affected by crusted scabies and advocacy for them is making a real difference in the efforts for control of scabies in the whole community.

Professor Bart Currie
The Menzies School of Health Research
One Disease Steering Committee Member

Malabam Health Board is committed to providing the very best in Primary Health Care to the Maningrida community and surrounding outstations. In recent years we have been fortunate enough to be associated with the passionate staff at One Disease via their Healthy Skin Program. They have achieved wonderful outcomes for Crusted Scabies patients and their families in our community.

Ray Matthews
Malabam Health Board Aboriginal Corporation
Program Partner

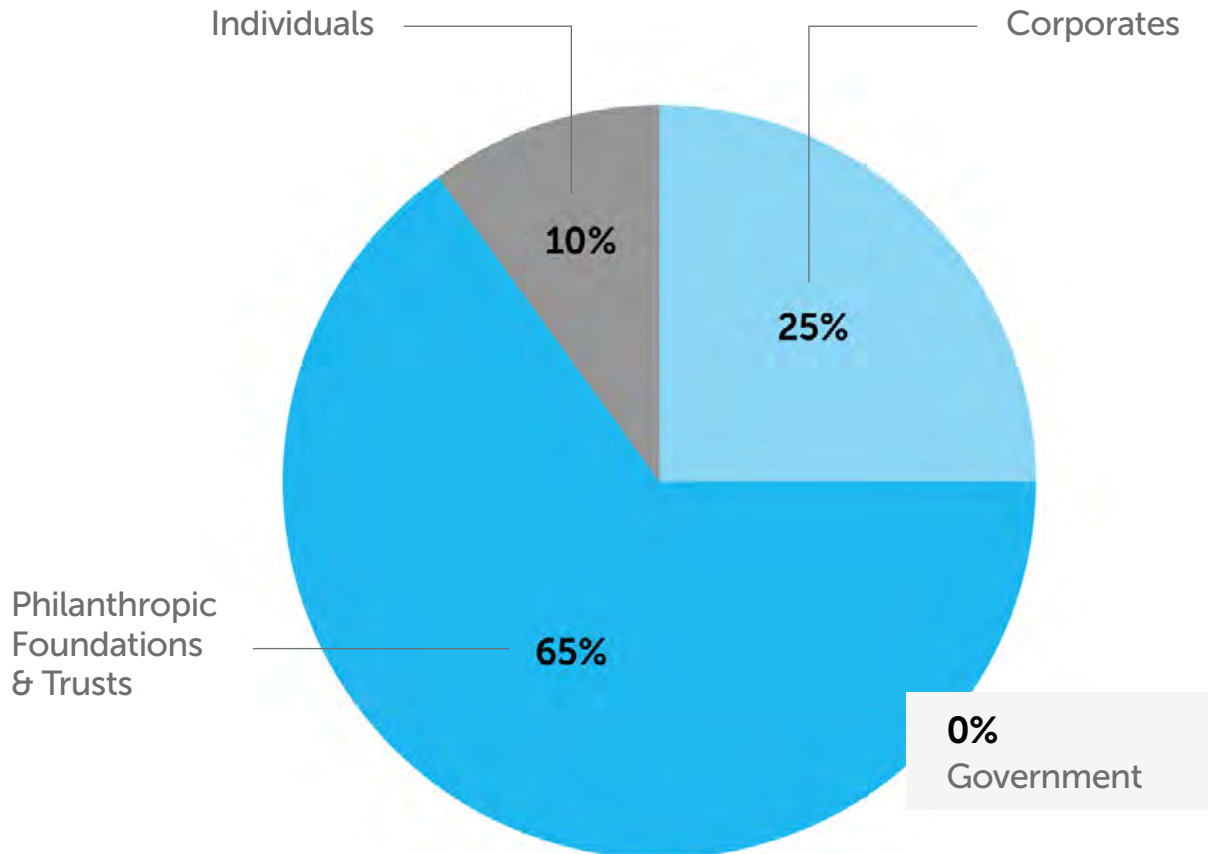
Financials

How much did we raise?



In **FY15**, we raised **\$1.329 million**, for our Healthy Skin Program

Where did this money come from?

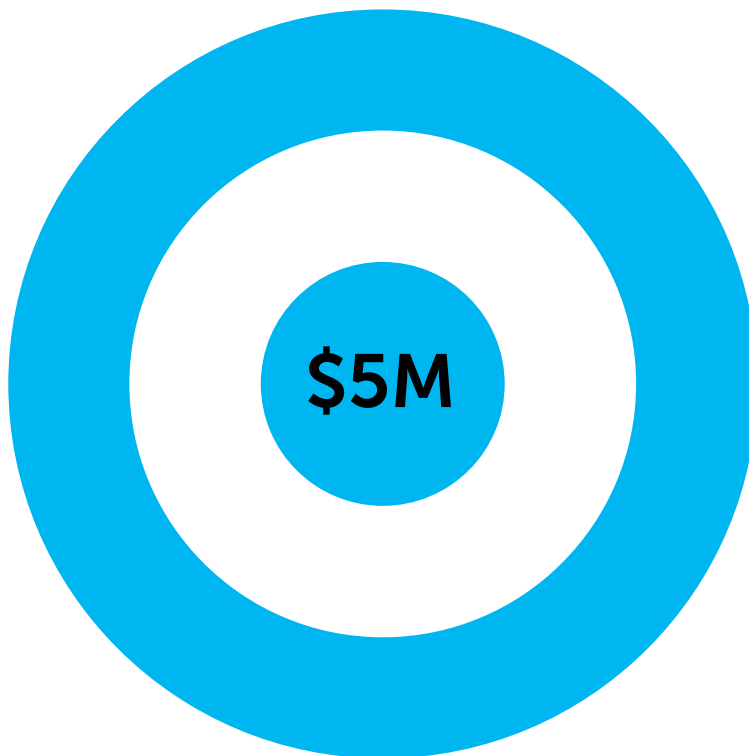


How did we spend this money?

We know that you want maximum donation dollars going directly into the field.

We do too. This is why we promise that **82 cents** of every dollar you donate will go to the field. Only **9 cents** will go into fundraising and development to raise awareness of our program through campaigns such as **#inkforgood**, and **9 cents** into administration- the cost to keep the lights on, no frills, just the essentials.

Our budget to eliminate CS in the NT by 2018 is:



Thank You

CS elimination wouldn't be possible without our valued supporters

Financial Supporters

Diamond

The Snow Foundation - Anonymous Trust - St George Foundation

Platinum

Merck Sharp & Dohme and MSD Australia - Aspen Foundation - Cameron Foundation

Gold

Sam White - Cassy Liberman - Thyne Reid Foundation - The Kimberley Foundation

Silver

Zambrero Staff - Jared Dunscombe Fund - The Annie & John Patterson Foundation - John and Myriam Wylie Foundation - Smith Charitable Trust - Gourlay Charitable Trust

Bronze

Dorothy and Bill Irwin Charitable Trust - Mary Mackillop Foundation - Patterson Pearce Foundation - Collier Charitable Fund - Magnolia Foundation - Sisters of Charity Foundation - AndyInc Foundation

For multiyear grants the support level is based on total donations received up to June 2015.

Program Partners & In-Kind Supporters

Miwatj Health Aboriginal Corporation,
Malabam Health Board Aboriginal Corporation,
Menzies School of Health Research, Northern
Territory Department of Health, Zambrero Human
Resources & Finance Teams, Kelly & Partners,
Aesop, Tonic Agency.

Volunteers

Alana Smith, Annika Tierney, Anthony Crescini,
Anthony Lieu, Amanda Huff, Charlton Tang,
Dan Siepen, Gabriela Coronel Palacios, Joshua
Garcia, Kelvin Hong, Kristine Purdy, Lauren
Thomas, Maeve Redmond, Meand Luk, Shikha
Chandarana, Torben Sko, Victoria Kinsman.



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