

ONE DISEASE

BELIEVE. CONNECT. INSPIRE

Annual Report 2016/2017



Contents

Who we are	3
Why Crusted Scabies: A snapshot of the problem	4
Message from our CEO	6
Our governance	7
Spotlight on our new board member – Professor Ngiare Brown	8
The year in review: Our progress towards the elimination of Crusted Scabies	9
Spotlight on our program team	16
Financial summary	21
Supporters and acknowledgements	22
How you can support us	23

Who we are

We are a not-for profit organisation, and the only group in the world focussed solely on understanding and eliminating Crusted Scabies. Our remote Indigenous communities of northern Australia have the highest reported rate of Crusted Scabies in the world.

Our mission has a single focus, with a clear, short timeline:

One Disease's elimination program will eliminate Crusted Scabies from the Northern Territory by the end of 2019 and across Australia by the end of 2022.

Our goal towards elimination is twofold:

- To improve detection, diagnosis and treatment of Crusted Scabies
- To prevent recurrences of Crusted Scabies in people who have been successfully treated.

Our work is undertaken in collaboration with Aboriginal Controlled Community Health Organisations, the Northern Territory government, and disease experts.

We are guided by an expert Advisory Board and funded by individuals, and philanthropic & corporate partners.



Why Crusted Scabies: A snapshot of the problem

Indigenous communities of northern Australia have the highest reported rate of Crusted Scabies in the world (Medical Journal of Australia 2014).

When left untreated,
50%

of people with Crusted Scabies will die within 5 years, often from secondary infections which lead to septicaemia.



Crusted Scabies on the feet (Source: Menzies School of Research Health)

Up-to
50%
of children and
25%

of adults are infected with scabies at some time.

Almost

70%

of Aboriginal children in some remote areas are infected before their first birthday.



Baby with secondary infection from scabies sores (Source: Menzies School of Research)

Crusted Scabies and scabies arise from poverty & overcrowding

Crusted Scabies develops from simple scabies in people who have a weakened immune system.

The tiny scabies mite burrows into the upper layer of the skin where it lives and lays its eggs.

In simple scabies, the number of mites at any one time is, on average, 10 to 15.

In Crusted Scabies, the scabies mites breed prolifically with numbers reaching the many tens of thousands, and in some cases millions.

The huge increase in the number of mites produce thick, warty crusts on the skin, which can cause great pain and skin disfigurement.

It can lead to an appearance alike to those with leprosy, which may cause feelings of great shame and isolation.

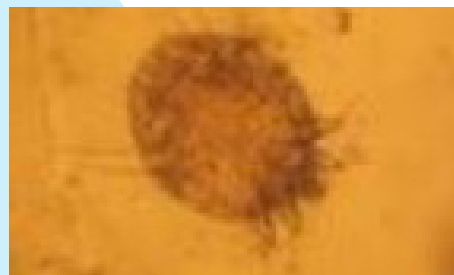
Scabies and Crusted Scabies are chronic diseases that cause serious health problems for our Indigenous communities through secondary infections, which can lead to rheumatic heart fever, heart disease and renal disease. Young Indigenous Australians in the Northern Territory are up to 122 times more likely to have rheumatic heart disease than their non-Indigenous counterparts (Australian Institute of Health & Welfare 2013).

This situation seems grim but Crusted Scabies can be controlled and prevented. Treatment, which usually requires hospital admission for isolation and intensive treatment with a combination of creams and oral medication can lead to a complete recovery of an acute episode.

A further challenge is that due to poor immune function, a person who has had Crusted Scabies is at great risk of reinfection from a person with a scabies infection, which is why One Disease's Elimination Program has an emphasis on the creation of Scabies Free Zones to minimise recurrences.

Crusted Scabies is highly contagious, and infests household members & visitors with scabies

Because they are infested with such large numbers of mites, people with Crusted Scabies are very contagious to others.



Scabies Mite

They spread scabies through skin-to-skin contact, and by shedding mites on their clothing, bedding, and furniture.

We believe no Australian should die from a preventable disease

Message from our CEO

"This has been a big year, if not the biggest, in One Disease's history."

Crusted Scabies Elimination is about two core goals and we've made significant inroads towards achieving both:

1. Detection/diagnosis & treatment:

There has been a

22.61% increase

of people confirmed and treated for Crusted Scabies in the past 12 months

2. Minimising recurrences:

We continue to be well under our

15% target

of Crusted Scabies recurrences.

This is truly shared success. To quote the remarkable Helen Keller: "Alone we can do so little, together we can do so much." I am proud of our fantastic team and Advisory Board. We are a critical element of this success story, but a small part. None of this would be possible without the clients and community who welcome us, the health sector staff who work tirelessly, and still find the time to partner with us to change Crusted Scabies health outcomes, and our amazing supporters who provide the all-important funds to make our work possible.

Exciting times are ahead for One Disease. Elimination is in our sights in the Northern Territory and we're starting with expansion plans for Queensland and Western Australia.

We hope that you will continue the journey with us.



Michele Bray | CEO

Our governance

One Disease advisory board

Our Advisory Board focuses on the broader strategic issues, and industry and community developments. Its principal role is to provide objective advice and high-level guidance, counsel and insights, specifically directed towards One Disease's charitable purpose (elimination of disease). The Board contributes to strategic planning within the guiding principles of cultural respect and true partnership with the Indigenous communities we work with. The Advisory Board members serve on a voluntary basis without remuneration.



Dr Sam Prince, Founder and Chair

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



Professor Frank Bowden

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



Professor Ngiare Brown

Ngiare is a proud Yuin nation woman from the south coast of NSW. She is a senior Aboriginal medical practitioner with qualifications in medicine, public health and primary care, and has studied bioethics, medical law and human rights.



Professor Jonathan Carapetis

As Director of the Telethon Institute for Child Health Research, Jonathan's work revealed a link between Strep A skin infections and the potentially fatal rheumatic heart disease. In 2008, he received the Northern Territory's Australian of the Year award.



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.



Professor Brian Schmidt AC

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 ground-breaking research on supernovae and the expansion of the universe.



Professor Hugh Taylor AC

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.

Company board

Our Company Board has overall responsibility for the governance and oversight of the affairs of One Disease, including monitoring performance and activities, legal and fiduciary compliance and supporting our Chief Executive Officer, Michele Bray, to manage the organisation. One of the Directors also acts in the capacity of Company Secretary. The Company Board members serve on a voluntary basis without remuneration.

Members: Dr. Sam Prince, Mr. Stephen Chapman, Ms. Katie Radjkovic

Spotlight on our new board member – Professor Ngiare Brown

Early in 2017, One Disease welcomed Professor Ngiare Brown to its Advisory Board. Along with the Indigenous people in community who guide us at a grass roots level every day, we are very fortunate now to have Ngiare guide us at a board level.

Ngiare was one of the first Aboriginal medical graduates in Australia and has made extensive contributions to Aboriginal and Torres Strait Islander health, research process, bioethics, policy, translation and practice. She is dedicated to supporting Indigenous communities to develop initiatives focused on cultural education, and breaking the intergenerational cycles of disparity.

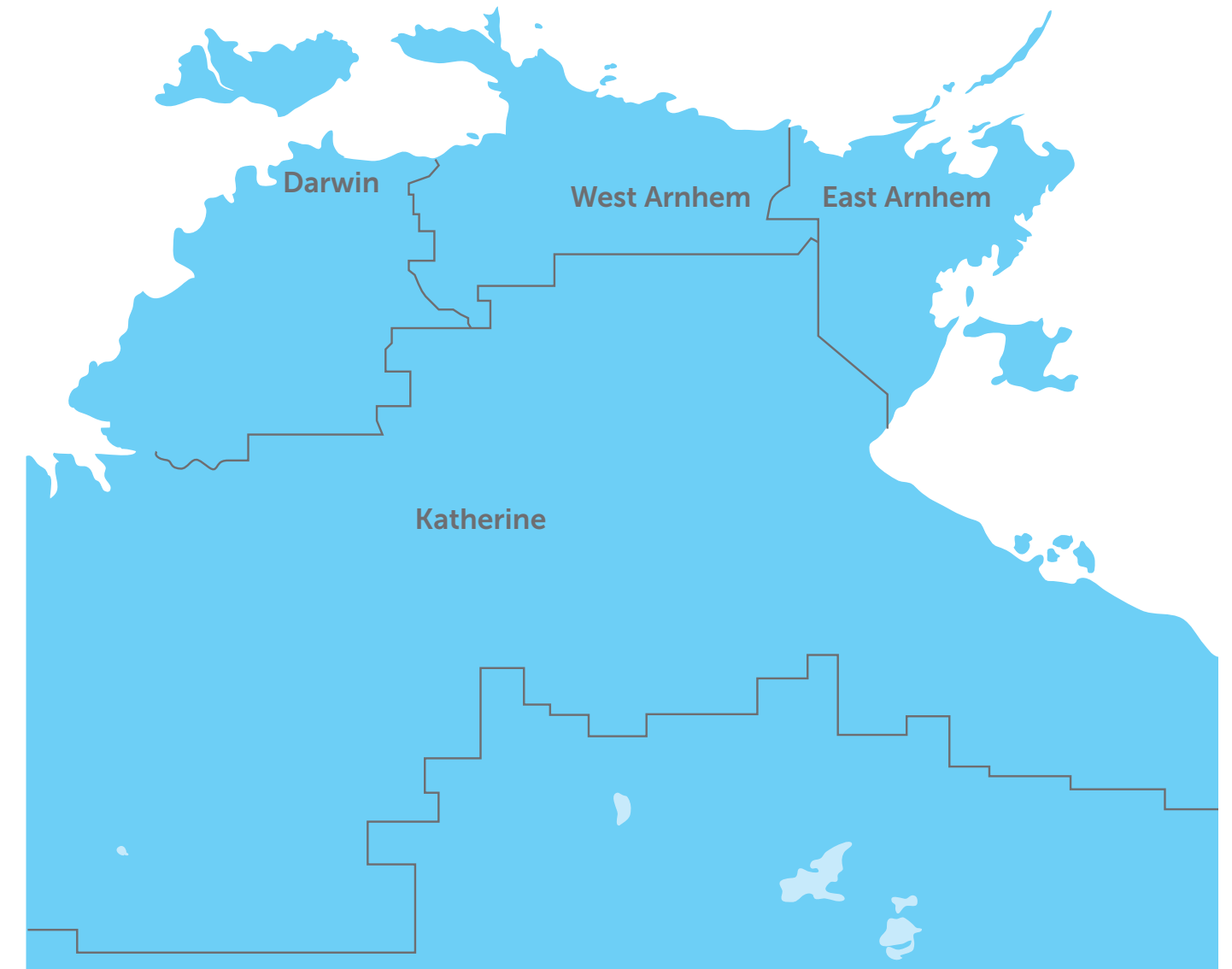
“It’s time to move away from the deficit model that is implicit in much discussion about the social determinants of health, and instead take a strengths-based cultural determinants approach to improving the health of Aboriginal and Torres Strait Islander people.”

- Professor Ngiare Brown

During her career so far, Ngiare has held positions in education, mentoring, clinical practice, research and advocacy. She is currently Executive Manager Research and Senior Public Health Medical Officer at the National Aboriginal Community Controlled Health Organisation where she is making a significant contribution to the research and reform agenda. She also has an academic appointment at the University of Wollongong as Professor of Indigenous Health and Education.

Ngiare’s position on the One Disease Advisory Board will further ensure that all our work involves true partnerships, culturally safe practices and strength-based approaches to empower people with Crusted Scabies, their families and broader communities.

The year in review: Our progress towards the elimination of Crusted Scabies



- Darwin: 50 people with Crusted Scabies identified; POP numbers: 11,116; health services we work with: 17
- Katherine: Clinical Audits undertaken, in only 12 months, 13 people with Crusted Scabies identified, treated and placed on electronic care plans; POP numbers: 11,098; health services: 23
- West Arnhem Land: On-track to being Crusted Scabies free; POP numbers: 7,436; health services: 6
- East Arnhem Land: Working with Miwatj Aboriginal Health Services and NT Health to embed systems and protocols to prevent recurrences of Crusted Scabies; POP numbers: 8,064; health services: 15

So far One Disease is 63 partnerships strong

In order to undertake our work, One Disease collaborates with Aboriginal Controlled Community Health Organisations and the Northern Territory Department of Health.

With their guidance, One Disease has expanded the Crusted Scabies Elimination Program to the entire Top End including Katherine. Partnerships with 63 health services have been formed.

Our successes against our two core Crusted Scabies elimination goals:

Goal 1. Improving detection and diagnosis of Crusted Scabies

Memorandum of understanding with the Northern Territory department of health has been updated and renewed, confirming our continuing partnership and shared aim to eliminate Crusted Scabies from the Northern Territory by the end of 2019

Crusted Scabies elimination plan

Following on from our previous years learnings, One Disease developed a new Crusted Scabies Elimination Plan, which outlines all the key actions and milestones, against a timeline, which will guide the elimination process. The creation of this plan was led by our Program Director, Michelle Dowden, and approved by our expert Advisory Board.

Detecting the disease

Over the last 12 months, there was a

22.61%

increase of people confirmed with Crusted Scabies - from 84 to 103. This is good news because detection and diagnosis is the first step towards elimination. Once detected, people with Crusted Scabies can be treated, and their home can be transformed into a scabies free zone, which will directly prevent recurrences of Crusted Scabies, and its precursor, scabies.

Crusted Scabies audits

Clinical audits were undertaken to ensure those confirmed as having Crusted Scabies meet the Northern Territory's new notifiability criteria. Of 488 suspected cases, only 85 met the criteria. This outcome was not unexpected as Crusted Scabies was only made notifiable in January 2016. However, it verifies that further education is required to ensure the health sector has current knowledge of Crusted Scabies detection, diagnosis and treatment and management protocols.

Revised guidelines

First written in 2014, One Disease has now updated the dedicated Crusted Scabies and Recurrent Scabies Guidelines in accordance with the new Northern Territory Notifiability Protocols for Crusted Scabies.

New technologies to improve the detection of Crusted Scabies

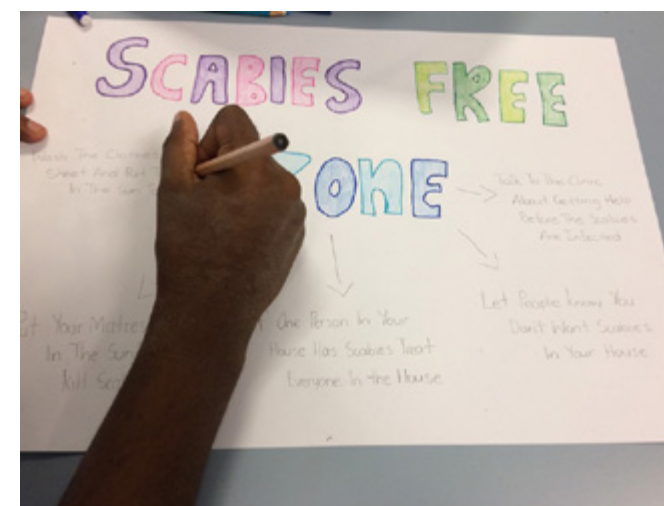


Burrow with Scabies mite as seen under the video microscope



Video Microscope

Currently, it takes between 48 hours to 5 or 6 days to confirm a Crusted Scabies diagnosis. During this time, people with Crusted Scabies continue to suffer and spread scabies to their household members. This is about to change, due to the pioneering Video Microscopy project, which will pilot the use of a portable, handheld video microscope to identify scabies mites. To be led by the dermatologist, Dr Dev Tilikaratne, use of the video microscope has the potential to shorten diagnosis time frames to only 24-48 hours.



Crusted Scabies education

Long neglected, the provision of Crusted Scabies education is crucial to foster understanding of the disease and the pathway to its elimination. Over the past year, One Disease program staff worked with Aboriginal Controlled Community Health Organisations to develop and deliver culturally safe education sessions to local health workers, hospital staff, people with Crusted Scabies, their families and their wider communities.

We engaged and worked with the following Indigenous health organisations:

- Katherine West Health Board, operating eight health service centres
- Malabam Health Board Aboriginal Corporation, operating one health service centre
- Miwatj Health Aboriginal Corporation, operating four health service centres
- Sunrise Health Service, operating nine health service centres
- Wurli-Wurlinjang Health Service, operating two health service centres
- Danila Dilba Health Service, operating one health service centre
- Laynhapuy Homelands Aboriginal Corporation, operating one health service centre

Over the last 12 months – 121 Crusted Scabies education sessions were developed & delivered reaching over 1570 attendees

Goal 2. Preventing recurrences of Crusted Scabies in people who have been successfully treated by embedding local systems and ensuring those treated live in a Scabies Free Zone

Recurrences of Crusted Scabies in people identified and treated currently remain less than

10%

Implementation of electronic care plans

Due to poor immune function, people treated for Crusted Scabies remain vulnerable to recurrences, which is why it is essential they each have an electronic care plan in place. A web-based document, the care plan includes the health history of the person with Crusted Scabies, and electronic prompts. This will assist health service staff to provide appropriate, comprehensive and timely care.

Over the last year, One Disease successfully negotiated the development of dedicated Crusted Scabies care plans in two electronic systems of the Northern Territory (PCIS & Communicare). The care plans have already been implemented in Communicare, and will be implemented in PCIS early in 2018.

26% of people confirmed with Crusted Scabies in the Northern Territory now have a care plan in place. Our target is 90%, which we will meet in 2018

Membership on the new Northern Territory hygiene network

Early in 2017, One Disease joined the new Hygiene Network in the Northern Territory. This is a collective of organisations with common interests: Scabies, Rheumatic Heart Disease, Trachoma and Crusted Scabies. The network has developed a NT Hygiene Strategy, and contributed to the Housing Referral pilot in the Maningrida community being conducted by NT Health. This pilot is an opportunity for housing repairs to be attended to for people who have had a recent diagnosis of a chronic condition, directly associated to hygiene related infections.



Significant program milestones

Ensuring our work is culturally safe and relevant

We have established a consumer reference network to provide advice on our work and ensure that community and people with Crusted Scabies remain our compass. The network's inaugural meeting was held in March 2017, and the plan is to increase the number of consumers involved, as we expand to new regions. All people with Crusted Scabies experience will be invited to attend.

Towards sustainability

Rather than growing the One Disease team, a clear step towards 'handing over' is that we are funding roles for 12 months in East Arnhem and Katherine. This is to undertake the grass roots work – to embed Crusted Scabies knowledge and systems, at a local level, in regions. We have successfully worked with health services in both regions to determine where the roles would be best placed (Centre for Disease Control) and to confirm service level agreements. Sustainability will be ensured for the longer term through measures like this.

Beginning our measurement & evaluation project

Crusted Scabies will be eliminated by in the Northern Territory by 2019 and nationally 2022, so it is vital to begin the external measurement and evaluation process. Initial work has begun, including determining the evaluation aims and team. The overall aim of the external evaluation is to develop a valid and reliable approach, supported by appropriate methods, which can clarify whether our elimination program has been effective in improving detection, diagnosis

and management of Crusted Scabies. This includes the prevention of recurrence, creation of scabies free household environments and ultimately the elimination of Crusted Scabies from Australia. The evaluation will also aim to assess whether the One Disease approach is effective as a transformational change model that can be replicated in other diseases in remote Aboriginal and Torres Strait Islander communities.

This project will be undertaken by One Disease and a consortium from the Public Service Research Group at the Business School, University of New South Wales, Canberra; the Australian National University Medical School, Australian National University and The Centre for Health Economics Research and Evaluation (CHERE), University of Technology, Sydney.

International value

One Disease's work is important not only in Australia, but potentially internationally. In 2014, scabies was added to the World Health Organisation's list of neglected tropical diseases (NTDs), in recognition of the very large burden of disease caused by the scabies mite. In March of 2017, it was recommended that the Scabies classification be elevated from Category B to Category A in the NTD profile.

Scabies is the only Category A NTD that doesn't yet have a roadmap for elimination. Currently, One Disease is the only organisation with on-the-ground programs addressing Crusted Scabies in the Northern Territory and is leading the way in developing a framework for its elimination.

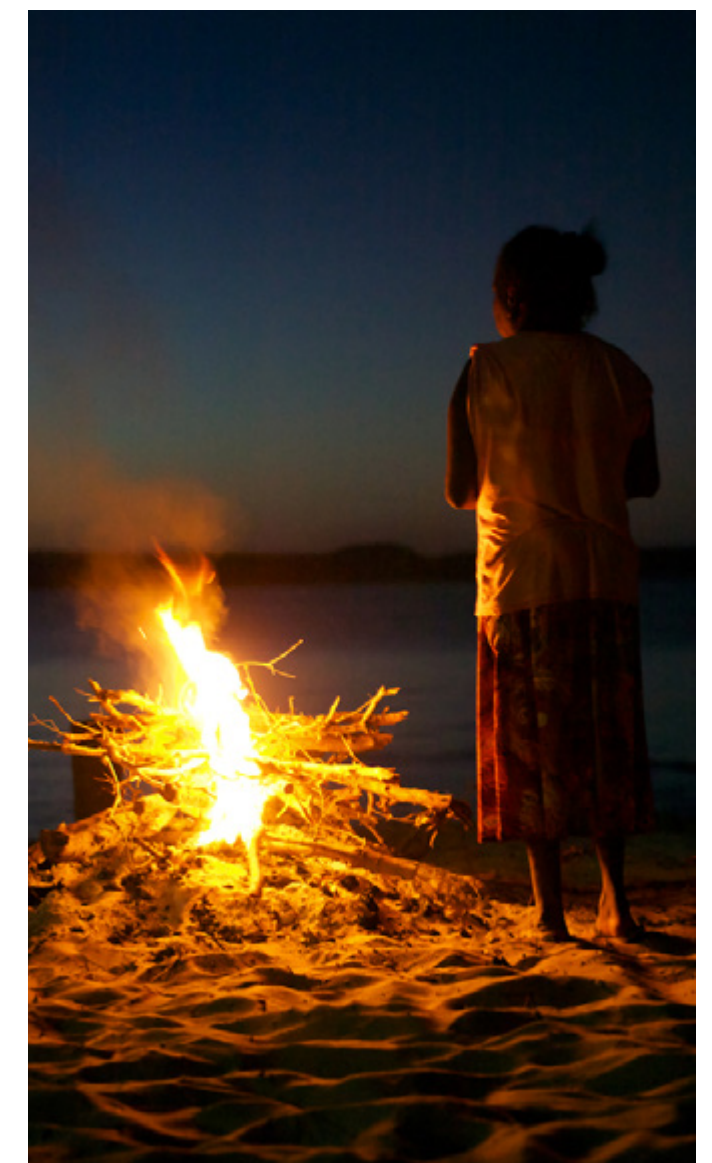
Our challenges

Stopping the spread of scabies

Maintaining Scabies Free Zones in scabies endemic areas is not unachievable but can be a challenge for the person who is susceptible and their families, especially given cultural movements. Cultural occasions mean that people are often on the move, going in and out of community for happy occasions such as festivals or sad ones such as funerals. Households are becoming vigilant about creating Scabies Free Zones but challenges arise when they are visiting or have visitors. Ensuring that everyone is free of scabies mites in these situations can be difficult. Encouraging the use of scabies treatment for everyone (including visitors) in the household is key.

Helping to prevent scabies in children

Households where children have had three or more presentations of scabies, in as many months, may mean there is a family member with undetected Crusted Scabies living in the house. Crusted Scabies leads to the presence of a very high number of scabies mites, which cause reinfection to other household members, including children. Local health services in remote communities are very busy, and additional visits to families can be time consuming. However, this approach is an essential strategy to uncover further cases of Crusted Scabies. We continue to work with local health services to inform them on the benefits of home visits for this situation. Our aim is to set up monthly reports in local clinical information systems to prompt home visits.





Supporting people with Crusted Scabies in urban settings

A substantial part of One Disease's work is with remote communities. However, we have come to understand that Indigenous people living in urban areas are also uniquely affected by Crusted Scabies. In March 2017, One Disease facilitated a workshop in Darwin that brought together nearly 50 disease experts and health care professionals to discuss the challenges Crusted Scabies presents in Darwin, where clients, often homeless (called long grassers), are falling through the cracks. We discussed how best to coordinate what can be fragmented clinical care for people with Crusted Scabies. Held at Charles Darwin University, it was a very productive day with new collaborations formed.



One Disease Program Director, Michele Dowden, presenting at the March workshop in Darwin.



Spotlight on our program team

The One Disease program team works from our Darwin office situated in the Menzies building. Led by our Program Director, Michelle Dowden, the other team members are Meg Scolyer, Senior Community Nurse; Irene O'Meara, Senior Community Nurse; Hannah Woerle, Public Health Coordinator; and Geneveive Dodds, Team Assistant.

What we do

The team's work in community includes initiating consultations on the formation of Crusted Scabies education workshops, and developing and delivering the workshops to Health Service staff including doctors, nurses and Aboriginal Health Workers, people with Crusted Scabies, their families and their communities.

Education is delivered in a variety of venues including meeting rooms of local health services, community halls, nursing homes, schools, creches, aged care facilities and people's homes. Education is tailored specifically to the audience and caters for cultural diversities.

The challenges and sometimes sadness associated with working in community, with people who have Crusted Scabies and their families is balanced by the richness and diversities of the cultures that our team experience. Their dedication and care for the people they engage with in remote communities is evident through their work as described below.



Strong Women Workshop held in Darwin, for all regions across the Top End. The group is watching the One Disease resource, called Stephen's Story, where Stephen Maymuru talks about his experience of having Crusted Scabies.



L - R Geneveive Dodds, Michelle Dowden, Hannah Woerle, Irene O'Meara, Meg Scolyer

Travelling to remote communities

The Northern Territory covers about one sixth of the Australian continent, so in any given week the team can travel many kilometres (by car, ferry or plane) working in remote communities.

If accessing by vehicle, there are several remote communities, which require river crossings. One such community which One Disease visits, is Gunbalanya. The trip requires a 4WD vehicle and an experienced driver due to unsealed roads, river crossings and the unique challenges of isolated locations. Gunbalanya, is a remote community approximately 302km from Darwin in the West Arnhem region, and has a population of approximately 1,100 people. The access route is via Cahill's (pronounced Kale's) Crossing on the East Alligator River. Cahill's Crossing is notorious for its high-density population of saltwater crocodiles (*Crocodylus porosus*) and is regularly closed due to season rainfalls and tidal flow.

"Sometimes I know I just have to be patient. I won't get there by the time I originally thought I would but I will get there."



More facts about where we work

There are more than fifteen major language groups across the different communities we work in, all with their own cultures and customs.

English is commonly a second-language in most NT remote communities. Local Indigenous health staff work alongside the One Disease staff, and as required, interpret information.

Over the last twelve months, 73 journeys were made to 23 communities

The shortest travel time to a community was 1 hour and 20 minutes to the community of Batchelor, 96km from Darwin and the longest was 12 hours to the community of Bulman, 620km from Darwin. Travel time is heavily influenced by the state of unsealed roads where corrugations, rainfall, sharp rocks, animals and tree falls can all affect the progress of a trip without warning.

Communities vary greatly in their population numbers and their infrastructure across the Northern Territory. The smallest community visited over the last twelve months by One Disease was the community of Peppimenarti, located approximately 330km from Darwin via an unsealed road.

Peppimenarti has a population of approximately 220 people and the community's infrastructure includes a shop, school, health service clinic and a police station.

The largest community visited by One Disease was the community of Maningrida, located in the West Arnhem Land region. This town centre services the local population of approximately 2,300 people, as well as more than 30 small outstations. The town's infrastructure reflects the larger population and is serviced by two supermarkets, a school, health service clinic, police station and public swimming pool. It has an art and cultural centre, and a tarmac airport.

Some communities visited such as Yirrkala in East Arnhem Land have a strong tourism industry with tours regularly organised so that visitors can learn about Indigenous culture, art and bush tucker. Many communities such as Borroloola have strong cultural ties to practices such as fishing, while others in different regions have connections to other hunting and gathering practices. Similarly, the history of communities can be varied; where some began as trading posts or missions such as Maningrida, other communities evolved when Aboriginal people moved from a larger community, such as in the case of Peppimenarti, which was created by people from Daly River to establish cattle enterprises.

Many Aboriginal communities in the Northern Territory have an art and cultural centre where the work of local artists is displayed and sometimes sold.



Cahill's Crossing on the East Alligator River, access route to Gunbalanya



An alternative way to visit Gunbalanya is via a 3-seater plane.



Fabric designed by Daly River artist, Aaron McTaggart



Crusted Scabies elimination in action

On a visit to Ramingining in the lead up to a holiday period, a One Disease team member was invited to the household of one of our long-term Crusted Scabies clients. The daughter (and carer) of the person with Crusted Scabies had requested a large amount of scabies cream & lotions. After examining the mother's skin, and a conversation with her carer, it was clear that there were no problems with scabies in the house. The carer had asked for the extra creams to protect her mum. She knew that there would be people coming to visit during the holiday and she was going to ask them to apply the scabies cream when they came into the house. This would mean their home would remain a Scabies Free Zone.

"I can see that our work is making a difference, people are wanting to look after their skin and are learning how to do this."




Financial Summary

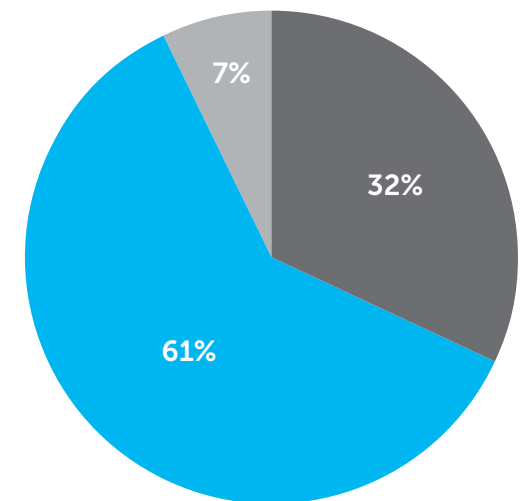
How much did we raise?

 In FY17, we raised \$841,861, towards the elimination of Crusted Scabies

Where did this money come from?

Source of donations

-  Corporates
-  Foundations & Trusts
-  Individuals



Our total budget towards elimination across Australia is **\$18 Million**

How will we spend the money?

92%

Work on eliminating Crusted Scabies

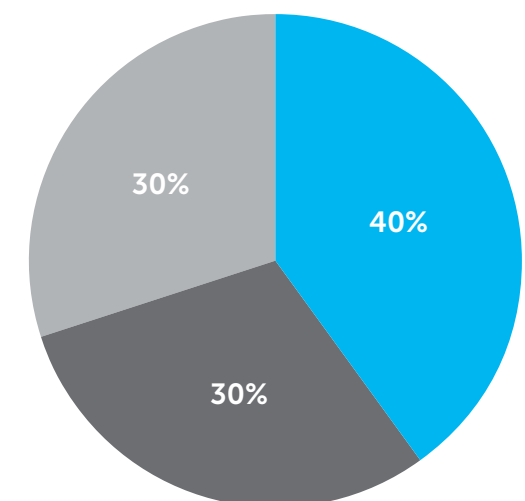
These funds go to develop, deliver and support work relating to raising funds for and eliminating Crusted Scabies.

8%

Administration

This is essential to the day to day running of our work and includes general overheads such as electricity, internet and office supplies.

Where will we spend the money?



-  Northern Territory
-  Western Australia
-  Queensland



Supporters and acknowledgements

We are extremely grateful for the commitment and support we receive from individual members of the community, as well as philanthropic and corporate trusts and foundations.

Thank you to all who are working with us to eliminate Crusted Scabies from Australia, specifically the Aboriginal Controlled Community Health Organisations and the Northern Territory Government.

We also sincerely thank our major donors who are assisting us to achieve our mission:

Anonymous Trust
Ian Hicks
Merck Sharpe and Dohme & MSD Australia
The Snow Foundation
Annie & John Paterson Foundation
Cameron Foundation
The Ian Potter Foundation
The Kimberley Foundation
Thyne Reid Foundation
Ghosh Family Foundation
Smith Charitable Fund
Zambrero Pty Ltd
Anonymous Fund
Milton Corporation Foundation

"When you're surrounded by people who share a passionate commitment around a common purpose, anything is possible." - Howard Schultz

How you can support us

Please consider making a financial gift.

By supporting One Disease you will become part of an extremely positive legacy, the elimination of a disease from Australia, and one (Crusted Scabies) that severely affects our remote Indigenous communities.

If you would like to find out more about our work, please visit www.onedisease.org or contact us on: (02) 9240 2307 or contact@onedisease.org.

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