

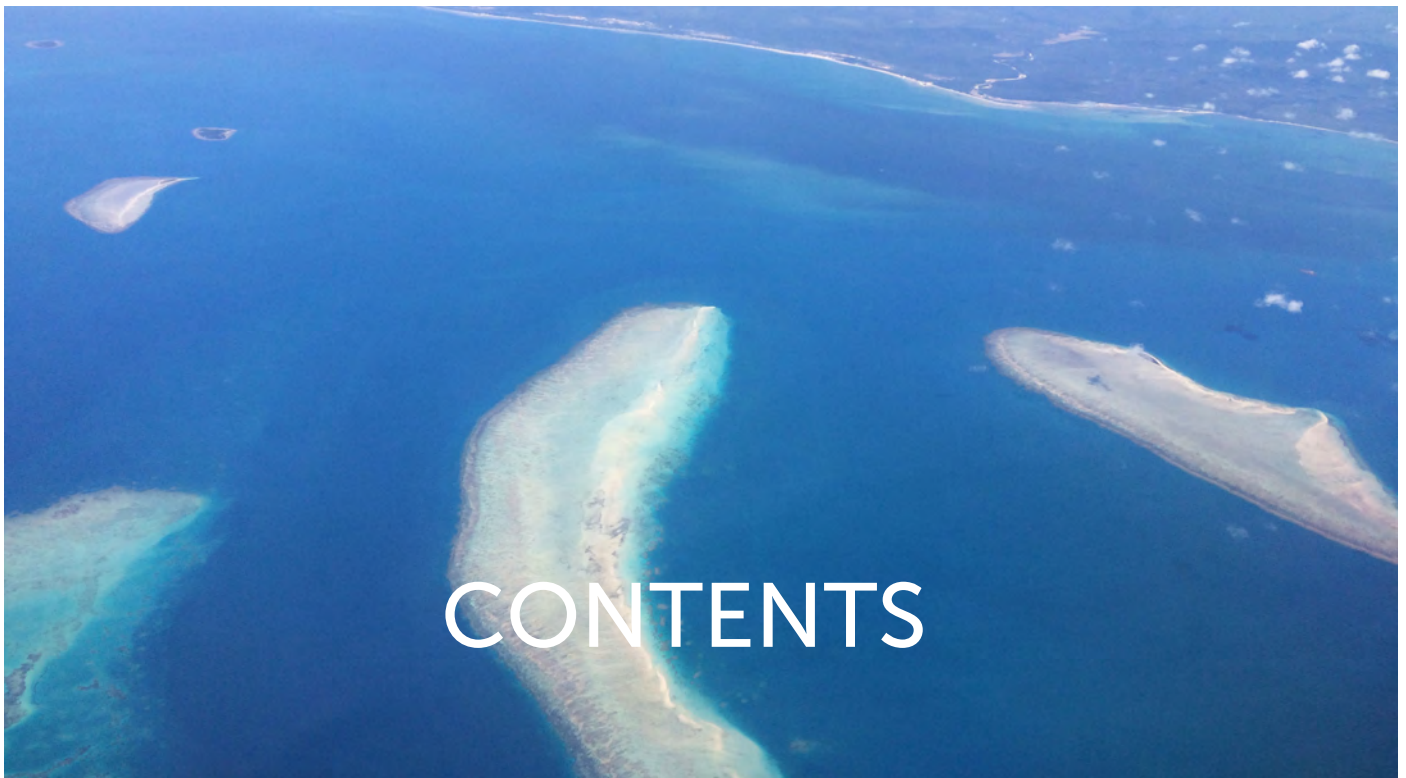
ONE DISEASE

BELIEVE. CONNECT. INSPIRE

Annual Report

2017-2018





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WHAT IS ONE DISEASE?

One Disease is a not-for-profit organisation, and the only group in the world focused on the detection, treatment and elimination of Crusted Scabies as a public health problem. Northern Australia's remote Indigenous communities 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 as a public health problem from the Northern Territory by the end of 2019 and across Australia by the end of 2022. We are currently on-track to meet this goal.

Our goal toward elimination is twofold:

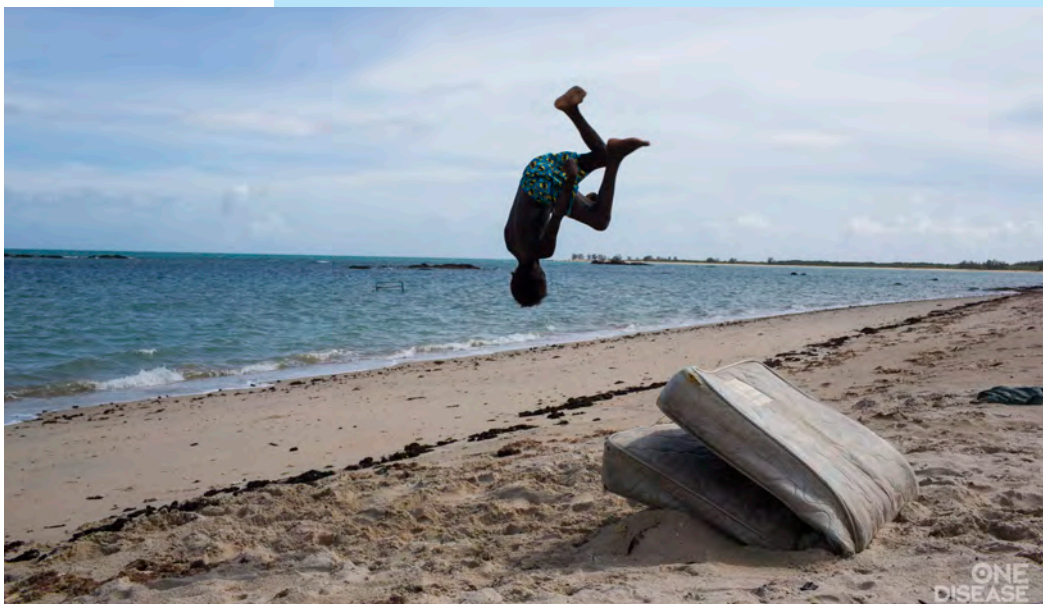
To improve detection, diagnosis and treatment of Crusted Scabies.

To prevent recurrences of Crusted Scabies in people who have been successfully treated.

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

We are guided by an Advisory Board of experts in our field and funded by donations from individuals and small groups, as well as by philanthropic and corporate partners who all believe as we do:

That no one should die of this preventable disease.





OUR GOVERNANCE

One Disease Company Board

The Company Board maintains overall responsibility for the governance and oversight of the affairs of One Disease. This includes monitoring company performance and activities, legal and fiduciary compliance, and supporting the Acting CEO, Michelle Dowden, to manage the day-to-day function of the organisation. One member of the Company Board also serves as Company Secretary. All members of the board serve in a volunteer capacity, without remuneration.

Members of the Company Board:

Dr Sam Price

Mr Stephen Chapman

Ms Katie Radjkovic

One Disease Advisory Board

Our Advisory Board focuses on One Disease's broad strategic issues, as well as industry and community developments. The principal role of the Advisory Board is to provide objective advice and high-level guidance, counsel and insights, specifically directed towards One Disease's charitable purpose (the treatment, reduction and elimination of Crusted Scabies). The Board contributes to strategic planning within the guiding principles of cultural respect and full partnership with the Indigenous communities we work with. All Advisory Board members serve in a volunteer capacity, without remuneration.

Meet the Advisory Board



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. Sam 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.



Professor Bart Currie

Professor Bart Currie is the head of the Tropical and Emerging Infectious Diseases team of the Global and Tropical Health Division at Menzies School of Health Research, Darwin. He is also an infectious diseases physician at the Royal Darwin Hospital, and since 2000, Professor of Medicine at the Northern Territory Medical Program at Flinders University.



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.

FROM THE CEO'S DESK

This year, the One Disease team have seen numerous successes as the organisation expands its scope to cover Queensland and Western Australia, following our ongoing success in the Northern Territory. Our team are a truly unique blend of people from a wide variety of backgrounds, all working together with a common goal. By working closely together over the past year, the Program and Development Teams have built enduring, respectful relationships that have enabled significant gains in the elimination of Crusted Scabies and in our deployment of a major funding grants campaign.



I personally found much inspiration this year in the story of the team of experts who came together to rescue the Wild Boars Soccer Team from inside a cave in Thailand. In this breathtaking story, the rescue team's impeccable coordination and planning were built on a foundation of trust and respect at a personal, organisational and institutional level. One Disease employs the same principles of respect and collaboration in our ongoing work with Indigenous communities and individuals as we continue in our mission to eliminate Crusted Scabies as a public health problem.

One Disease is the only not-for-profit organisation worldwide to be working on the elimination of Crusted Scabies. We are immensely proud of our work over the last 12 months and acknowledge that without partnerships at individual and community levels, our mission would be impossible to carry out. It takes an enormous amount of work to coordinate across so many communities all over the Top End, but the end result is a program that values the experience of the individual and upholds dignity and respect at every level.

It is a testament to our mission and work that this year we applied for Australian Government Department of Health funding and were successful. Significant funding support for our elimination program has been provided for three years.

I would personally like to thank our entire One Disease team, our partners in community and all of our contributors for their ongoing support and mateship. There's a long road ahead to eliminate Crusted Scabies, but the journey is made markedly easier by the exceptional input of our various teams. I'm proud to work with all of you.

I would also like to make a special thank you to our outgoing Advisory Board member, Dr Terence Kwan. Terence has been an invaluable member of our Board for the past several years, and we are grateful for all of the work he did with us over that time. From myself and the rest of the team at One Disease, we wish him all the best for the future.

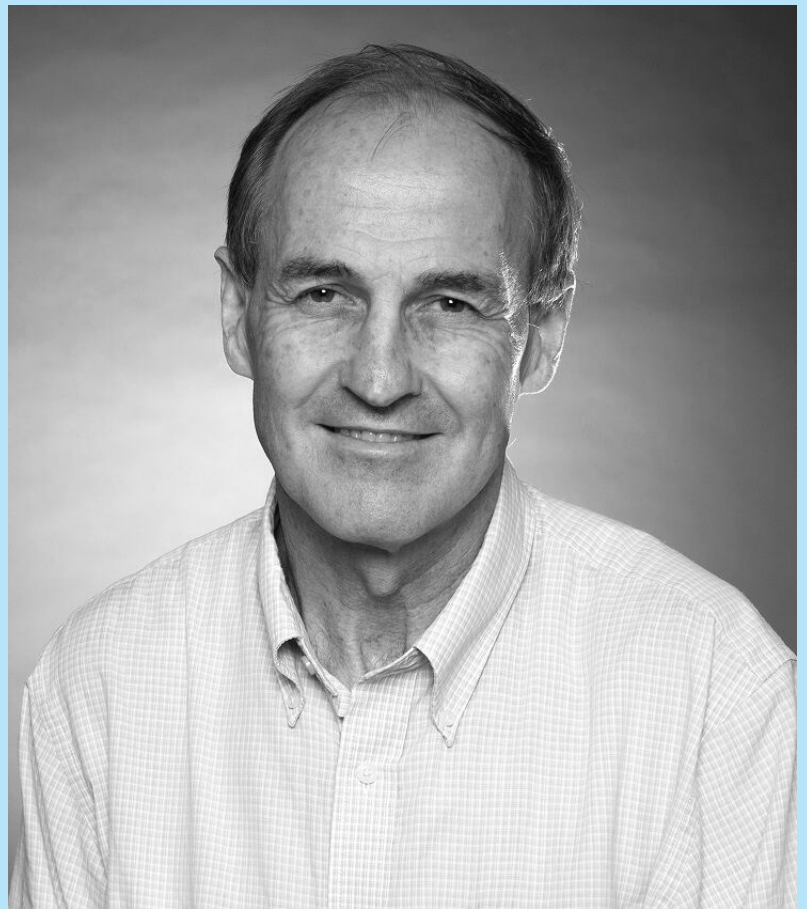
I look forward to continuing our vital work together as we head into next year. Thank you to all.

Michelle Dowden, Acting CEO

INTRODUCING OUR NEWEST BOARD MEMBER: PROFESSOR BART CURRIE

This year, One Disease welcomes a new member onto our Advisory Board, Professor Bart Currie. His CV reads like a greatest-hits record of medical research and practice in the Top End: Professor Currie is the head of the Tropical and Emerging Infectious Diseases team at the Global and Tropical Health Division of Menzies School of Health Research, Darwin. He is an infectious diseases physician at Royal Darwin Hospital and Professor of Medicine at Flinders University, in the Northern Territory Medical Program. He is an adjunct Professorial Fellow at Charles Darwin University and an adjunct Professor at James Cook University. He is the Director of RHD Australia and Hot North, working to improve health outcomes for rural and remote communities in the Top End.

Professor Currie's passion in his work is for coordinating links between clinicians, public health colleagues and other service providers, laboratory scientists and the community. Professor Currie's wealth of knowledge and experience in the field of infectious tropical diseases, and his lasting commitment to bringing together research, practice and community make him an enormous asset to the One Disease team. We are thrilled to have Professor Currie on our board and look forward to putting his expertise to good use.



WHAT IS CRUSTED SCABIES?



Crusted Scabies is a serious public health problem in rural and remote communities, particularly in the Northern Territory, Western Australia and Queensland. It has an estimated occurrence of one person in every 496 but this number continues to fluctuate as One Disease carry out our work, as until now it has been largely overlooked by the public health system.

Crusted Scabies is a particular problem for remote Indigenous communities, with those of northern Australia having the highest prevalence of the disease in the world - higher even than developing areas like rural Nigeria or the Solomon Islands.

Crusted Scabies affects people with scabies who also have compromised immune systems, often due to other chronic illnesses. It is particularly devastating in small, overcrowded communities, due to its highly infectious nature. Crusted Scabies is transmitted through skin-to-skin contact, or from shedding of mites to clothing, bedding and furniture. This is why One Disease's programs place an emphasis on not simply treating the disease, but teaching our clients, their family and their community to prevent further occurrences through improved skin hygiene practices and education in identifying symptoms before they become serious.

We estimate that 50% of people afflicted by Crusted Scabies die within five years due to health complications and secondary infections resulting from the disease.



**AFFECTS 1
IN 496**

50%
*OF UNTREATED
PEOPLE WITH
CRUSTED SCABIES
WILL DIE WITHIN 5
YEARS*



SIMPLE SCABIES:

10 TO 15 SCABIES MITES BURROWING UNDER THE SKIN

CRUSTED SCABIES:

TENS OF THOUSANDS, EVEN MILLIONS

Unlike in simple Scabies, where a person might have 10 to 15 scabies mites burrowing under their skin and laying eggs, cases of Crusted Scabies can involve hundreds of thousands, or even millions of the mites on one host. The activity of all these mites causes thick, warty crusts to develop on the surface of a person's skin, particularly around the hands, feet and joints. This causes great discomfort and skin disfigurement, which can itself result in feelings of isolation and shame that discourage the person affected to seek crucial medical attention.

Scabies is endemic in remote Aboriginal communities of the Northern Territory, with up to 30% of children infected at some time.

Despite this grim picture, Crusted Scabies is treatable and preventable with the right precautions and education. We believe that no Australian should die of a preventable disease, and we intend to eliminate Crusted Scabies as a public health problem in our country.

Through secondary infections, scabies and Crusted Scabies can lead to rheumatic heart fever, heart disease and renal disease.



HOW DOES ONE DISEASE ENGAGE AT A LOCAL LEVEL?

A CASE STUDY

An Indigenous woman in her 40s with recurrent Crusted Scabies lives in a remote community. She resides in hostel-style accommodation with a shared kitchen and bathroom facilities. Residents don't have much control over washing and cleaning of these facilities.

The woman has limited knowledge of Crusted Scabies and its treatment requirements. She needs information and support to overcome shame and to build her confidence that she herself can get rid of the Crusted Scabies.

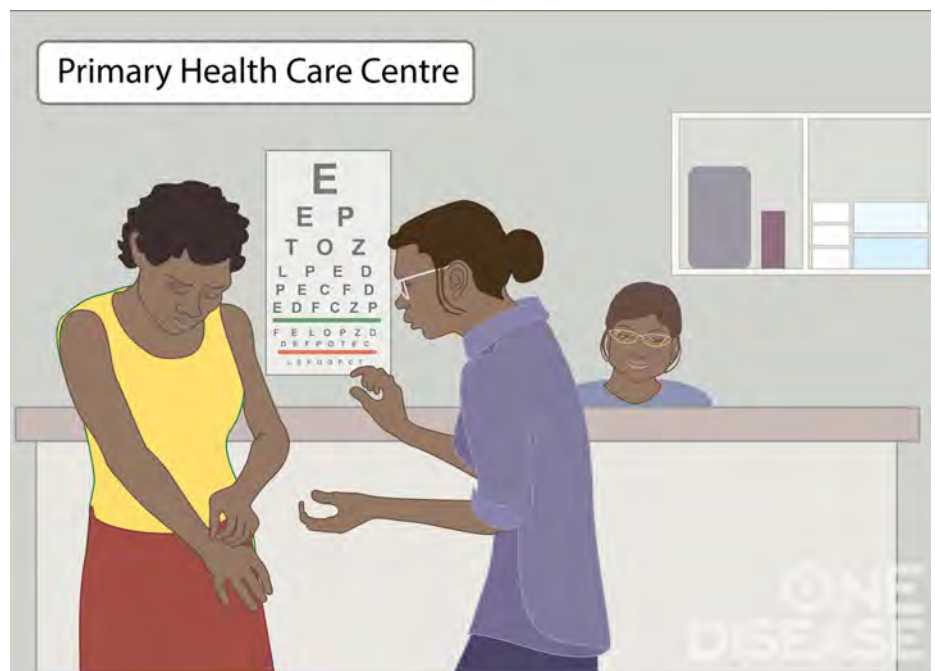
She also needs help to find ways to deal with and improve the inadequate washing facilities and other problems of living in close quarters that make it difficult to maintain healthy skin.

STEP ONE: IDENTIFY THE PATIENT AND PROVIDE EDUCATION

Enter One Disease staff: they provide education about Crusted Scabies, they encourage her to access the local clinic for treatment, and coordinate cleaning of her residence to facilitate the creation of a Scabies Free Zone.

STEP TWO: WORK WITH THE CLINIC

One Disease staff then work with clinic staff to follow-up with the woman in her community and assist her by providing practical support to overcome the aspects of her housing situation that make it difficult to treat her illness.





STEP THREE: CLEAN THE HOUSE AND HELP THE PATIENT TAKE CONTROL

The house is cleaned. The Aboriginal Health Practitioner from the clinic visits the woman at home - providing education, topical cream and encourages her to continue visiting the clinic for treatment.



STEP FOUR: CONTINUE SUPPORT, PERSONALISE A CARE PLAN

The health practitioner offers the woman showers at the clinic and helps to administer the cream to ensure it is applied correctly. A personalised care plan for treatment and management of the woman's Crusted Scabies is implemented.





WHAT ARE THE BENEFITS OF ELIMINATING CRUSTED SCABIES?

Eliminating Crusted Scabies as a public health problem will mean achieving the elimination of a globally neglected and preventable disease from Australia. It will improve health outcomes for Aboriginal and Torres Strait Islander peoples through a decrease in the prevalence of other associated illnesses such as kidney disease and rheumatic heart fever - diseases that often occur in people with Crusted Scabies and create complications for treatment, and in particularly severe cases can result in death.

The elimination of Crusted Scabies will involve the establishment and maintenance of a proven skin health care routine for Indigenous Australians, a routine which can then be replicated and adapted more broadly to create lasting change.

SO, HOW ARE WE TRAVELLING?

KEY FINDINGS FROM OUR PROGRAM'S EXTERNAL EVALUATION

Evaluation is an essential management tool, which helps to ensure that health activities are implemented as planned and to assess whether desired results are being achieved.

Over the past year, in partnership with One Disease, a consortium from the Public Service Research Group, School of Business, University of New South Wales Canberra; The Centre for Health Economics Research and Evaluations, University of Technology Sydney; and the Medical School, the Australian National University Canberra, evaluated the One Disease Crusted Scabies Elimination Program.

Some Key Findings:

The One Disease Elimination program is well regarded. Our program fits within the health service context and is acceptable to participating providers. Implementation of the program is well established in Top End services.

Treatment is improving in hospital and the community. The Increased length of hospital treatment suggests patients

are completing treatment more often. This is a major achievement. Furthermore, following completion of hospital treatment, more frequent contact was provided in the community. This is a positive result, particularly as the Crusted Scabies patient cohort has high levels of disadvantage.

Crusted Scabies Recurrences are reducing:

The overall trends in recurrence are positive. Most patients did not have a recurrence in the follow-up period. In all but one case the grade of disease was less at the recurrence. The duration between episodes is six months or more, with Crusted Scabies being reacquired in the community following a long length of initial treatment.

Scabies Free Zones are difficult to implement:

Maintaining a Scabies Free Zone is challenging as it requires coordination and treatment of all household members. Aboriginal leadership is critical for working with communities and households to provide education and support for a

Scabies-Free environment. In addition, the involvement of communities and households, as active partners, in passing on the Crusted Scabies story and developing a community approach to supporting scabies-free households is needed.

Elimination:

Moving towards the elimination of Crusted Scabies in the context of endemic scabies is difficult as cured patients return to scabies endemic environments. However, the One Disease program has the key elements of a disease elimination approach.



STRONG PROGRESS AGAINST OUR PROGRAM GOALS

Since our Crusted Scabies Elimination Plan was endorsed by the Advisory Board in April 2017, we have made significant progress in the Northern Territory towards achieving our two major Elimination Goals.

Goal 1:

To improve the detection and diagnosis of Crusted Scabies.

Goal 2:

To prevent recurrences of Crusted Scabies in people who have been successfully treated by embedding local systems and ensuring those treated and their families live in a Scabies Free Zone.

The best statistical indicator that we are on track to achieving our Elimination Goals is the current rate of recurrence of Crusted Scabies in individuals detected, diagnosed and treated by

One Disease. We use this measure to indicate our ongoing success in the field, and whether there are improvements we need to make to our implementation of our systems. It gives us a more accurate representation of our effect on the population of people with Crusted Scabies than the rate of occurrence, because as we discover more individuals in remote communities, that number can fluctuate year to year.

Currently, 1 in 496 Indigenous people living in the Northern Territory has Crusted Scabies. The Crusted Scabies rate of recurrence after One Disease identification, intervention and treatment is only 3.3%. We are very proud of this figure, as it demonstrates that our efforts to treat people and then keep their homes and communities Scabies-Free are working in the majority of cases. We are also seeing increased lengths of hospital treatment stays in people One Disease has been able to detect, diagnose and schedule for treatment. This indicates that more people are completing their course of treatment before returning to their communities.



HOW DO WE IMPROVE OUR OUTCOMES?

To compound on the success of our Crusted Scabies Elimination Plan so far, we have been in more frequent contact with our clients' communities, to ensure those treated for Crusted Scabies are followed-up regularly and receive adequate support to remain Scabies-Free going forward. This is perhaps the most important stage of the elimination process: ensuring that our clients have the tools and systems in place to take their continuing health into their own hands.

This year, we have also successfully negotiated the inclusion of recall and reminder prompts within the existing electronic patient systems of the Northern Territory specifically for people being treated for Crusted Scabies. This change will allow health professionals to recall patients and provide care at appropriate intervals, increasing the effectiveness of treatment and significantly decreasing the likelihood of Crusted Scabies recurrence.

Currently, 75% of our confirmed Crusted Scabies clients have a Recall and Reminder prompt set up in their health systems. We want to achieve a Rate of Recurrence of 0 per cent, and this is one of the tools we think will best help us achieve that goal. The recall and reminder system allows for the generation of reports, so that healthcare professionals can monitor the progress of Crusted Scabies patients more accurately in the long-term.

We will need to continue to improve and develop our Crusted Scabies detection programs as we expand into Western Australia and Queensland. A clear challenge will be that both these states have an electronic information system for clinical patients that is not easy to navigate across multiple providers. This means that instead of identifying people with Crusted Scabies through a centralised network, we will need to collect the information more locally, in partnership with local clinics, particularly the Aboriginal Health Services. Our commitment to local engagement and coordination puts us in good stead to overcome this hurdle in the coming year.

HEALTHY SKIN SYMPOSIUMS AND GRANT INFORMATION WORKSHOPS

In the second half of this year, One Disease held two major Healthy Skin Symposia, and Grant Information Workshops for our inaugural small grant recipients; organisations working with remote Indigenous communities.

The Symposia provided opportunities for outreach into regional centres from which we aim to extend our programs into local communities. The grant workshops focused on the topic of our first small grant round, the creation and maintenance of Scabies Free Zones. The first of these events were held in Cairns on 9 and 10 October.

The Symposium in Cairns provided an opportunity for the One Disease team to discuss detection, diagnosis, treatment and community management of Crusted Scabies with Queensland health workers. It was a chance for teams to discuss strategies, prior successes and areas we can improve on.

We had several guest speakers, covering topics such as Rheumatic Heart Disease, skin health surveillance and treatment, as well as the services that Wuchopperen and Orange Sky provide in achieving positive health

outcomes in under-serviced areas. We were honoured to have Gudjugudju welcome us to Country, and the Hon. Warren Entsch present to officially open the Symposium.

At the Grant Information Workshop, where we welcomed our successful applicants for our first round of community grants, there were representatives from organisations based in Cairns, Mornington Island, Townsville, Mount Isa, Mackay and Thursday Island - just to name a few. The workshop provided a continuation of our discussions from the day prior, while also providing an opportunity for recipients to discuss their individual projects and how they will promote creating Scabies Free Zones in their communities.

It was a fantastic opportunity for these teams to meet and network - to collaborate and to begin to build a support base. As our first formal events in Queensland as part of our expansion interstate, the Symposium and Grant Information Workshop were very successful. The fresh perspectives of our grant recipients and the chance to coordinate with even more communities as we expand is essential to us.





The second Healthy Skin Symposium and Grant Information Workshop were held in Alice Springs in early November. This Symposium allowed us to continue delivering our discussion points on Crusted Scabies, and how we can most effectively reach new community influencers.

Arrernte Elder, teacher and artist, Kumalie Riley welcomed us to country and we had a highly experienced range of speakers at the Symposium, covering our focus areas of Crusted Scabies and associated illnesses such as Rheumatic Heart Disease and Chronic Kidney Disease.

We held a discussion on the social determinants of health, which is essential when working, as we do, with rural, remote, and often-overlooked communities. We spoke about Crusted Scabies

notification and the Public Health response, and there was a group discussion at the end of the day where participants were encouraged to ask questions about the program, and to give input on how the One Disease team can best service Central Australia.

At our second Grant Recipient Information Workshop, we met with our Northern Territory grant recipients to discuss how to dispel myths surrounding Crusted Scabies, the work involved in setting up and maintaining a Scabies Free Zone, and to provide a place for them to network, much as we did in Cairns.

The Healthy Skin Symposiums and our Information Workshops were well attended by passionate members of local communities and were an invaluable experience for us at One Disease, to engage at the

local level and really get a sense of what these areas need and how we can best provide the support required.

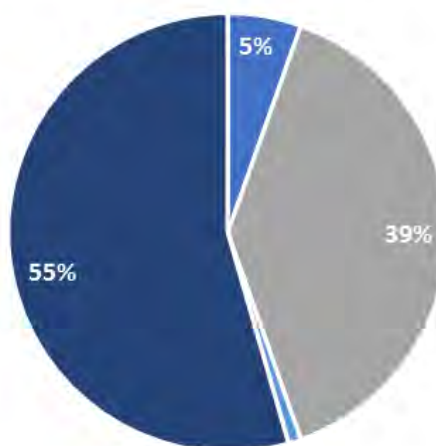
Smaller healthy skin events and grant workshops were also held in Tennant Creek and Darwin. The plan is to hold a larger event in Tennant Creek and a Healthy Skin Symposium in a regional area of Western Australia in 2019.

We would like to extend our sincere thanks to all our guest speakers for their time and expertise; your ongoing commitment to continuing this vital education around skin health in the Northern Territory and Queensland is greatly appreciated.

ONE DISEASE: A BRIEF FINANCIAL SUMMARY

In Financial Year 2017 we raised \$2,006,150.68 towards the elimination of Crusted Scabies as a public health problem.

55 per cent of this money came from a Government grant, 39 per cent from Foundations and Trusts, 5 per cent from Corporate donors and the remaining 1 per cent from individual donors.



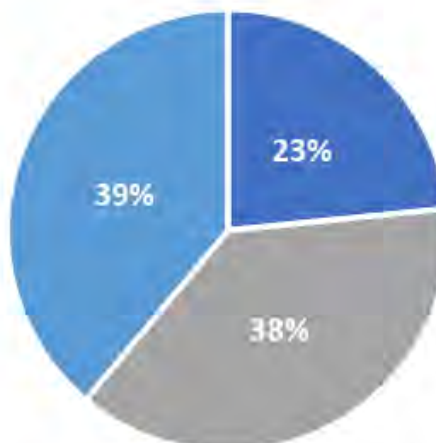
TOTAL FUNDS RAISED

- Corporates
- Foundations & Trusts
- Individuals
- Government

One Disease's total budget towards elimination of Crusted Scabies is \$11.7 million.

90 percent of this money goes towards developing, delivering and supporting our work relating to eliminating Crusted Scabies as a public health concern in Australia.

The remaining 10 per cent makes up our administration costs: any of the essential expenses that go into keeping One Disease up and running.



FORECASTED EXPENDITURE BY STATE FY19 TO FY23

- Northern Territory
- Western Australia
- Queensland

ACKNOWLEDGEMENTS

One Disease would not exist without the commitment and support we receive from individual community members, philanthropic and corporate sponsors. We are very grateful for all the support our donors, volunteers and community liaisons provide.

Thank you to all those who are working hand in hand with us to eliminate Crusted Scabies as a public health problem in Australia. A special thank you specifically to the Aboriginal Controlled Community Health Organisations, the Australian Government Department of Health, and the Northern Territory Government.

We would also like to sincerely thank our major donors, who are assisting us to achieve our mission.

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The Bruce Hyams Foundation
Sisters of Charity Foundation
Cameron Foundation
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PLEASE SUPPORT US

Please consider making a financial gift to One Disease in our mission to eliminate Crusted Scabies. By supporting One Disease, you become part of an extremely positive legacy: the only organisation in the world working to eliminate Crusted Scabies as a public health problem. This is a disease that almost solely affects Australia's First People. With your help, we can improve the health outcomes for Indigenous Australians and all those living with Crusted Scabies for years to come.

One Disease is supported by the Australian Government Department of Health

ONE DISEASE

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