

BI-ANNUAL REPORT
NOV - MAY **2013**

DGR & TCC ENDORSED
ABN 34 436 287 194

**ONE
DISEASE
AT A TIME**
IMAGINE. PARTNER. ELIMINATE.

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FOREWORD FROM THE CEO

I am delighted to report on the further success that your support of One Disease at a Time (One Disease) has enabled in 2013. Our first initiative continues to be the elimination of crusted scabies and scabies in the participating communities of East Arnhem and this report expands on our most recent achievements.

An outstanding result is the 65% and 76% reduction in the number of days that scabies and crusted scabies patients (respectively) have been hospitalised in the past year. This victory means that many people, who before felt debilitated and excluded by this harshly visible disease, are now more confidently able to participate in community life. They share some of their stories in this report.

These are the most recent wins in our broader mission to treat and prevent this disease nationwide. With your help, our programs are redefining the way we partner with Indigenous Australians to solve common problems. Yours is an investment in a healthier and happier future for all Australians. I thank you sincerely for sharing and supporting our vision to eliminate one disease at a time.



Samantha Cran

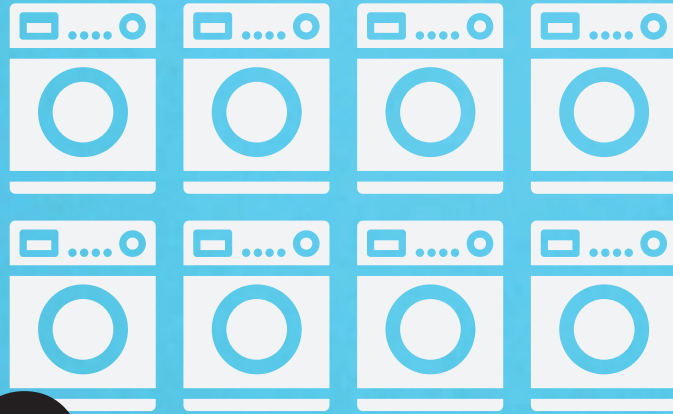


Georgina Byron

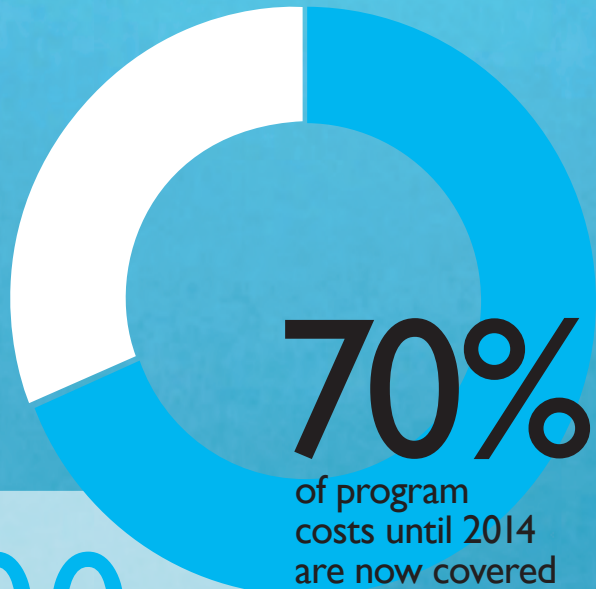
"To eliminate scabies is a mammoth task to tackle yet such a huge health issue and so necessary. We have been delighted with the progress of One Disease. In early 2011 we provided an initial \$100,000 to kick-start the pilot. We knew Sam and his team were exceptional and the project with their sensitive approach to remote communities was innovative and attractive. After my visit to Arnhem Land in August 2012 where I witnessed their work and met the people delivering the program, it reinforced my belief and we promptly made a further 2 year funding commitment."

Georgina Byron, CEO, The Snow Foundation

LAUNCH OF SPIN PROJECT



8 communities in Arnhem land welcomed the Spin Project, helping to prevent the spread of disease by improving access to washing machines



\$375,000+

Additional funding secured

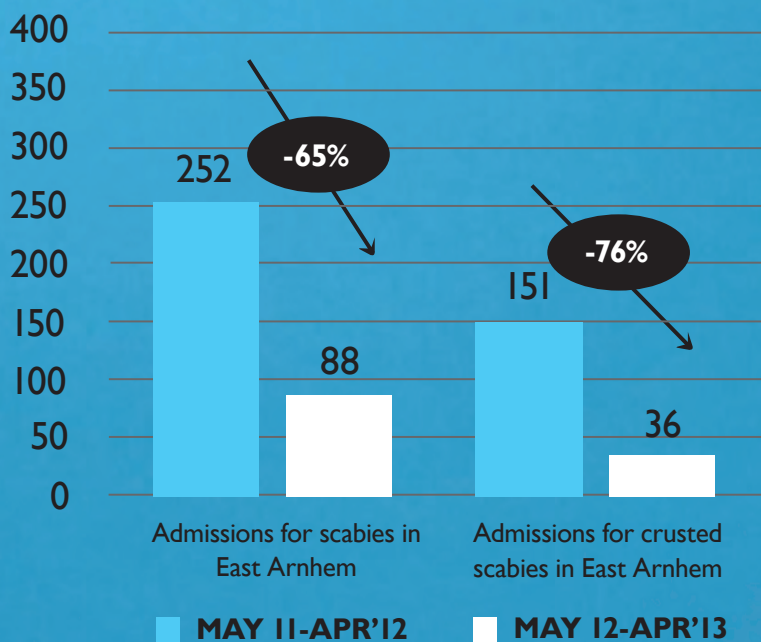




INAUGURAL PROGRAM SUCCEEDS IN YIRRKALA

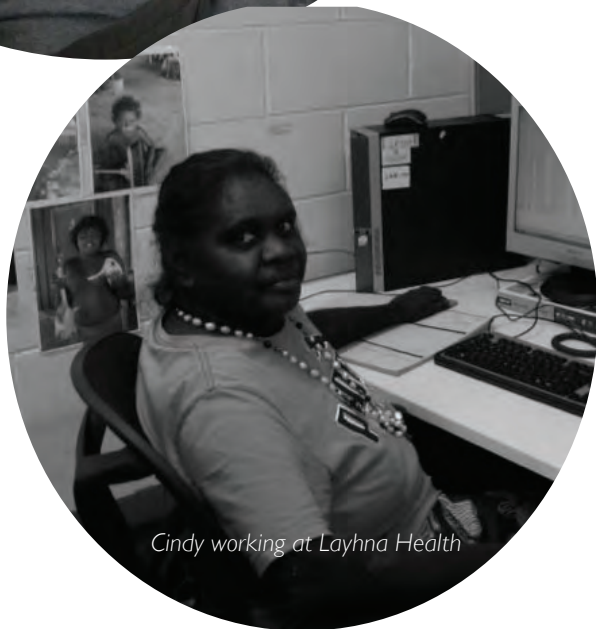
All known crusted scabies cases treated and managed since August 2011

SIGNIFICANT REDUCTION IN THE NUMBER OF DAYS THAT SCABIES AND CRUSTED SCABIES PATIENTS HAVE BEEN HOSPITALISED IN THE PAST YEAR





Faye Alvoen and Cindy



Cindy working at Layhna Health



CINDY'S STORY

Cindy and her son live with two other families in their home in Yirrkala. She is an educated, strong lady who is always ready for a laugh. Since 1983 she has been in constant discomfort with itching and feeling unwell linked to scabies and crusted scabies. She got on with life as best she could, but eventually after a fall and complications related to crusted scabies she became wheelchair bound in 2008.

Cindy would seek treatment at the local health clinic and at the local hospital, spending on average 37 days in hospital for crusted scabies every year since 2008. However due to previous protocols for managing crusted scabies, support and care was never consistent and ongoing, resulting in constant relapses and habitual anguish.

Eventually she was overcome and could no longer work because of the disease. Despite this she never lost hope of one day returning to work.

She first met Faye from One Disease at a Time in July of 2012 at the Yirrkala Health Clinic. Faye offered what had been previously lacking with consistent support in the form of new protocols initiated by One Disease for chronic care management. For Cindy who always persevered, this was motivation enough to try to beat the disease again.

She started with regular application of Benzyl benzoate cream mixed with tea tree oil and within a couple of months she started seeing improvements.

After 9 months of daily, turning to weekly, and now monthly treatment and monitoring by Cindy herself with the team from One Disease, she is now free of crusted scabies and has 'shiny, healthy skin'. She is back at work at Layhna Health, feeling good and finally happy again. She is even making steps without her wheelchair, strong enough to face the world again.

SNAPSHOT OF THE HEALTH

GALIWIN'KU (1890 COMMUNITY MEMBERS)

- Washing machine audit and repairs made as a part of the 'Spin Project'

MILINGIMBI (1017 COMMUNITY MEMBERS)

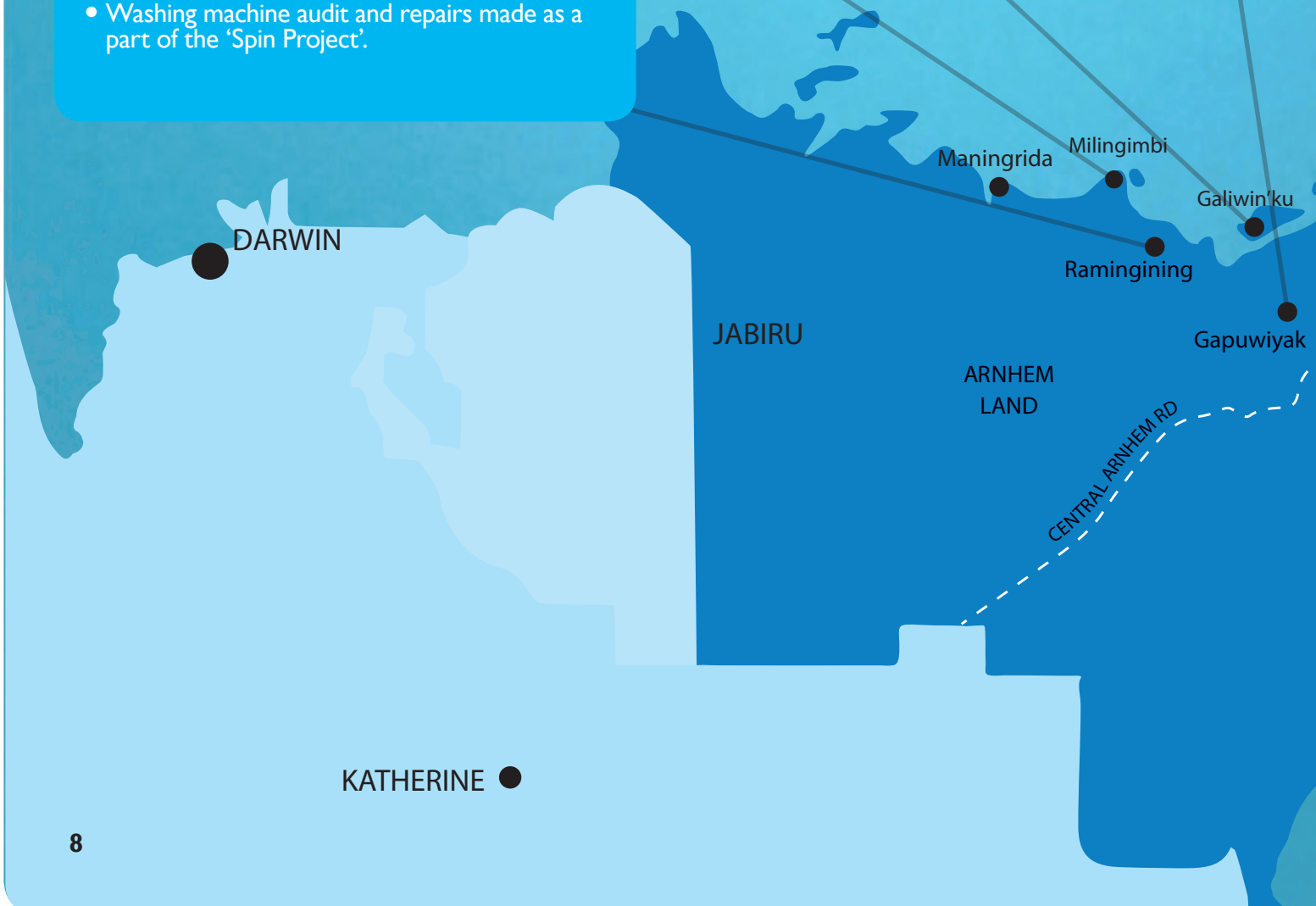
- Washing machine audit and repairs made as a part of the 'Spin Project'.

RAMINGINING (828 COMMUNITY MEMBERS)

- Washing machine audit and repairs made as a part of the 'Spin Project'.

GAPUWIYAK (825 COMMUNITY MEMBERS)

- Washing machine audit and repairs made as a part of the 'Spin Project'.
- Two trips to community to initiate work on crusted scabies, in partnership with local health worker Teresa Guyula.
- Early identification and management of one crusted scabies patient.
- One in-service update and education session at local health clinic.



KATHERINE ●

HEALTHY SKIN PROGRAM ACTIVITY

YIRRKALA (1250 COMMUNITY MEMBERS)

- Frequent ongoing monitoring and support of 6 crusted scabies patients – no serious relapses since August 2011.
- Brief hospitalisation of two patients in Dec, early detection meant relapse was not serious.
- Continuing general monitoring of scabies in community through local Community Health workers (Wayalwanga, Bamuniya, Bandiyal, Ritjilili).
- Two in-service updates and education sessions with Yirrkala Health Centre and Gove District Hospital.
- Partnering with key influential families and elders to plan Healthy Skin event (June 2013) and secured support from Gurrutu’Mirri Mala group (community nominated leaders).
- Scabies education session with expectant mothers from the Frangipani Unit from the local maternity ward (first of a series).
- Washing machine audit and repairs made as a part of the ‘Spin Project’.

GUNYANGARA, GALUPA & BIRITJIMI (350 COMMUNITY MEMBERS)

- Scabies rates continue to be very low.
- Monitoring and support for one crusted scabies patient.
- Assisting Miwatj with identification of a new crusted scabies patient and offering light touch support for Miwatj to manage the case.
- Mini skin and child health education sessions.
- Local community worker, Sharyl Yunupingu, working in her community to monitor scabies rates and assist with treatment.
- Local Community Coordinator Wayalwanga Marika working in her community to monitor rates of scabies and assist with treatment.
- Washing machine audit and repairs made as a part of the ‘Spin Project’.
- One in-service update and education session at local health clinic.
- Case conferencing commencing with Miwatj Health to ensure shared care of Crusted Scabies clients.





HEALTHY SKIN

PROGRAM GOALS

Our program is a multifaceted and effective partnership with Indigenous Australia to eliminate crusted scabies and scabies as a public health issue. It consists of five key goals with multiple strategies under each. Here we review our progress over the past 6 months relating to each goal.

TREAT CORE TRANSMITTERS

- Crusted scabies case management
- Supporting families with recurrent scabies

SUSTAINED REDUCTION

- Community surveillance for early treatment
- Social marketing for early treatment and compliance
- Development of next generation scabies cream

POINT IN TIME PREVALENCE REDUCTION

- Healthy Skin, Healthy Homes events
- Ivermectin mass drug administration

OPERATIONAL ENHANCERS AND ENABLERS

- Building community workforces
- Education tools for clinical staff and patients
- Sustainable washing machines
- Monitoring and evaluation
- Targeted operational research

SCALING-UP IMPACT

- Advocacy and systems-wide change
- Developing systems for national-roll out



CRUSTED SCABIES

A NEGLECTED AND MISUNDERSTOOD DISEASE

Crusted scabies is a far more severe form of simple scabies. It is a highly infectious condition that occurs when an individual's immune system is not able to control scabies mite reproduction. The disease is disfiguring and can impact life expectancy due to complications from secondary bacterial infections. Family members often suffer recurrent scabies, skin sores and complications.



Magnified scabies mites

TREATING CORE TRANSMITTERS

Crusted scabies case management is underway in 3 of the 6 communities in East Arnhem. For the past 18 months, Yirrkala has been the test community and promising results have been achieved there (hypothesise, test, evaluate, adapt & evolve the program). Most patients who develop crusted scabies will have a life long susceptibility to developing the disease. Treating crusted scabies as a chronic condition, which involves ongoing support and regular contact with patients has lead to the success we have seen to date. We have also started regular 'case conferences' to ensure shared care of patients between One Disease at a Time and their Health Service. Now we are taking the program to Gapuwiyak at the request of community and stakeholders. It is our goal to map all cases of crusted scabies in East Arnhem, and support Healthy Skin Events in all communities that request assistance in the region. In addition to established communities there are dozens of homelands (remote communities) which we have started to support (eg. our partnership with Laynhapuy Homelands Aboriginal Corporation, Laynha Health Service).

YIRRKALA

We have continuing success with 6 crusted scabies cases being controlled under the management of One Disease nurse Faye. Two cases relapsed due to temporary absence of a male health worker and breakdowns of supply chain for medication. Early detection and correction of these issues meant the relapses were not serious.

We've noticed simple scabies rates can increase during times of community movement for things such as funerals. As well as ongoing monitoring to encourage treatment, our team is devising strategies to overcome the unwanted side-effects of important communal events (eg. Healthy Skin events and mobile clinics etc).





GAPUWIYAK

One case of crusted scabies has been confirmed and is under ongoing tailored treatment as per the new CARPA guidelines. One Disease nurse Helen will oversee the implementation of the chronic care plan for this patient.

Community members in 3 households were also treated for scabies in a 'mini' skin day to minimise the crusted scabies patient's exposure to scabies upon re-entry to the home.

Helen will visit Gapuwiyak on a monthly basis to assist those families dealing with recurrent scabies.

GUNYANGARA

One new case of crusted scabies has been confirmed and is under ongoing tailored treatment as per the new CARPA guidelines. One Disease is assisting with light touch support for Miwatj staff to manage the case.

LAYHNAPUY HOMELANDS

Using the new CARPA protocol (for chronic disease management of crusted scabies) the homeland health service is monitoring one patient (that has moved from Yirrkala) and a new crusted scabies patient they have identified.

One Disease at a Time have signed a memorandum of understanding with Laynha (Homelands facilities & services) to support their work and share data to ensure shared care and best outcomes are achieved.



*Alex Kop and Jeff Cook
from Layhnapuy*



Scabies education over damper with Alex Kopczynski, Wayalwanga Marika & Bamuniya Marika



SUSTAINED REDUCTION OF REPRODUCTIVE RATE

NEW SCABICIDE TREATMENT

There are growing concerns over increasing resistance to current scabicide treatments.

In order to future-proof our program, One Disease has partnered with drug development company Medicines Development to investigate new treatments for scabies (ideally ready for usage in 2-5 years). Medicines Development has expertise in progressing products through the development process from drug screening through to clinical development within a regulatory framework. Among others, they have worked with Nexpep Pty Ltd to develop what may become the world's first vaccine against coeliac disease.

Initial work has begun reviewing existing treatments for other diseases that may be suitable for use against scabies as well (eg. head lice treatments).

Thus simplifying future regulatory processes.

Peter John River near the homeland community of Rorruwuy and 44km west of Nhulunbuy

POINT IN TIME PREVALENCE REDUCTION

OUR FIRST HEALTHY SKIN HEALTHY HOMES EVENT IN YIRRKALA

Since August 2011 we have participated in healthy skin events in Ramingining, Gunyangara, Birritjimi, Gapuwiyak, Galupa and Numbulwar. This will be the first event in which we are taking the lead role as a part of a broader community engagement and education strategy.

Following the sustained success of the crusted scabies chronic care management plan, we can now progress with the next phase of our program which includes strategies to reduce the rates of simple scabies via community wide education and application of treatment creams at a Healthy Skin Healthy Homes event.

Alex Kopczyński and other One Disease staff members have started extensive elder engagement in Yirrkala to gain support for the event on June 3.

Community wide skin screenings and education sessions will be carried out one week prior to the event as well as screening after the event to demonstrate the effectiveness of the skin day.

The entire One Disease team will attend the event from which they intend to develop a Healthy Skin implementation manual, which can be used in other communities.

Update at time of printing: We send our condolences to the family of Mr Yunupingu who passed away June 3 in Yirrkala. Out of respect to his family and community our Healthy Skin Event was postponed. At the request of the community a scaled back event was held on June 11.



OPERATIONAL ENHANCERS AND ENABLERS



Washing machine repairs



LAUNCH OF THE SPIN PROJECT IN THE 5 MAJOR COMMUNITIES IN EAST ARNHEM AND 3 MINOR COMMUNITIES IN THE GOVE PENINSULA

To eliminate crusted scabies and scabies as public health issues, we need to also look at causal factors relating to the spread of the disease. Lack of access to working facilities for washing clothes and bedding has been identified as a contributor to the spread of scabies and its secondary infections.

Together with Miwatj Health and with funding from OATSIH (Office of Aboriginal and Torres Strait Islander Health), we launched the Spin Project (Washing Machine Djäma) aiming to improve the sustainability of washing machines across the region. Preliminary research indicates that machines in East Arnhem Land last on average 1-2 years before they breakdown. This compares to a 10-15 year lifespan in the rest of Australia.

The program will focus on several areas:

- Regular servicing visits to each community to inspect household machines, diagnose faults and conduct on-the-spot repairs
- Stocking of spare parts to enable more on-the-spot repairs to be made
- A training program for local workers to create self-sustaining support in community
- Education and social marketing campaign for community members
- Promotion of a loan scheme to enable fast-track access for households in need
- Advocate for the standardisation of washing machines models sold locally
- All results are reported back to the community via posters and progress will be monitored and reported back at 6 monthly intervals.

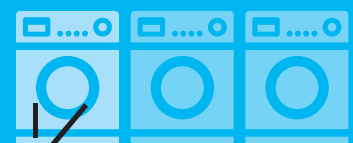
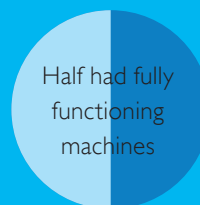


Bruce Patterson,
Spin Project

WASHING MACHINE DJÄMA AT A GLANCE

Launched in
YIRRKALA, GAPUWIYAK, GALIWIN'KU,
MILINGIMBI, RAMINGINING, GUNYANGARA,
GALUPA AND BIRRIJIMI

480 HOUSEHOLDS VISITED = 90% OF OCCUPIED DWELLINGS



3 of households didn't have a functioning machine

99
machines were repaired back to fully functioning status

Most faults can be prevented with better installation and rectified with regular servicing

OPERATIONAL ENHANCERS AND ENABLERS

MONITORING AND EVALUATION UNDERWAY

A formal monitoring and evaluation plan for the Healthy Skin program has been established in partnership with external providers (Tropical Health Solutions).

There are three core streams of measurement:

Qualitative and quantitative measures relating to progress of disease elimination in participating communities

Monitoring of implementation in line with program values and principles of putting community first, doing no harm, and empowering community to help themselves.

General program and business evaluation (such as program refinements, efficiencies in use of funding, training and career development)

We will continuously adapt and track changes in our monitoring and evaluation plan as our program strategy evolves. We believe in selecting the right KPIs that focus on delivering long-term value to the communities.

Baseline data collection will be completed by June 2013. The first external audit of data will take place in August 2013.



FIRST INTERNAL RESEARCH INTO LIVE MITES

We are about to launch live mite research into understanding the relative importance of environmental transmission of scabies from individuals with crusted scabies. We will be assessing their home environments, and together with patients, developing strategies to decrease the risk of recurrence.

Alex Kopczynski, Operations Manager, is leading the project, and has engaged Professor Rick Speare from James Cook University to provide technical guidance. The project will run for approximately 12-18 months and we expect to report outcomes and implications for our program and general treatment of crusted scabies and simple scabies by the end of 2014. Timing is dependent upon access to new or relapsed cases of crusted scabies and the coordination of this with available resources.

EDUCATION TOOLS FOR CLINICAL STAFF AND PATIENTS

- Developed fact sheet for Gove District Hospital to aide health staff treating crusted scabies, and to ensure a coordinated approach is taken to the care of all patients.
- In the process of developing a guide for health staff to deal with crusted scabies so One Disease at a Time only has to offer light touch support.
- In the process of developing a guide for health staff to deal with households that have repeated scabies infections.



Scabies mite by renowned Australian artist Terry Yumbulul

The background of the entire page is a dense, close-up photograph of coral rubble. The coral pieces are in various shapes and sizes, ranging from small, rounded fragments to larger, elongated, and more complex structures. The colors are primarily off-white, light beige, and cream, with some darker spots and a few pieces showing a reddish-brown hue. The texture is highly porous and irregular.

SCALING UP IMPACT

SHARING TO CREATE ADVOCACY

To maximise the impact of our work, we improve the effectiveness of existing health services by catalysing broader systems changes and structural changes.

We have shared our program results and reflections at a variety of industry conferences and workshops; The Continuous Quality Improvement Collaborative Workshop at AMSANT in Darwin (November), the Healthy Skin, Healthy Lives workshop in Perth (December) and the annual meeting of Australasian Society for Infectious Diseases in Canberra (March).

We're also in the process of developing and then plan to publish two case studies. The themes for these case studies are 'The importance and impact of crusted scabies in remote communities' and 'Chronic disease approach to crusted scabies and results to date'.

GROWING TEAM



Ritjilili Ganambarr

Community Coordinator.

Ritjilili has a background as leader in health initiatives

amongst her community, previously working as a Strong Women Strong Culture Strong Babies Worker.



Sharyl Yunipingu

Community Worker.

Sharyl is a young leader within her small community and has

taken on the role of maintaining low rates of scabies by promoting healthy skin in Gunyangara.



Helen Kempton

Scabies Nurse Coordinantor.

Helen has been involved in the health industry for 30 years

having worked as a nurse and midwife in both metro and regional areas. She has spent much of the last 12 months working at the Health Centre in Gunyungara and brings not only a wealth of clinical experience, but also strong relationships in community. She will be responsible for introducing and supporting the roll out of crusted scabies case management throughout East Arnhem Land with light touch support.



Bruce Patterson

Spin Project Technician

Bruce has lived in Yirrkala for 24 years and manages the Yirrkala

Banana Farm. He is a trained electrician and works with One Disease to assess and repair faults to washing machines in East Arnhem as a part of the Spin Project.

VOLUNTEERS

Volunteers are crucial to the ongoing success of One Disease;

Michelle Holland – Graphic Design, **Anthony Lieu** – IT, **Simone Thompson** – Financial & Legal,

Alana Smith – Copywriter, **Georgia Kartas** – Copywriter, **Richard Barley** – HR, **Georgina Taylor** – Fundraising,

Kyrra Engle – Fundraising, **Elenoa Seru** – Fundraising, **Kathryn Martin** - Graphic Design, **Alison Moebus** - Nurse

*Wayalwanga, Alex, Ritjili
and Chris in Yirrkala*



*Happy kids after Lyclar
application in Ganyagara*



Lyclear application and cleaning with Helen Kempton in Guryangara



NEXT 6 MONTHS...

Within our five key goals, we will be focussing on these key strategies and objectives in the coming months;

- Identify and confirm all cases of crusted scabies in East Arnhem.
- Develop a better understanding of the spectrum of disease from simple to crusted scabies (with definitions of categories).
- Build on and extend the Healthy Skin Program (including a Healthy Skin event in Ramingining and other communities if support is requested, growth of the community workforce, strategies to reduce spread during ceremonies, phase two of the spin project).
- Review options for expansion of Healthy Skin Program outside of East Arnhem.
- Begin work with traditional and medical practitioners to assess efficacy of local customary skin remedies.

ONE DISEASE AT A TIME WOULD LIKE TO ACKNOWLEDGE OUR GENEROUS SUPPORTERS FOR THEIR INVESTMENT INTO THE HEALTHY SKIN PROGRAM

PHILANTHROPIC SUPPORTERS



- Gourlay Charitable Trust
- Bray Kargas Family Fund
- Wildfire - Monash University Rural Health Club
- Rotary Club Great Lakes
- Kimberley Foundation
- The Jibber Trust (Rasmussen Foundation)
- Nicholas Curtis (Lynas Corporation)
- Office for Aboriginal and Torres Straight Islander Health



Judy Lewis

"St. George Foundation is all about helping the little guys (grassroots charities). When we heard about the new thinking that One Disease at a Time was applying to the very old problem of crusted scabies we were delighted to help. We believe that our very small investment in this approach, in its very early days, will have a huge and long lasting impact not just on the children of Arnhem Land but for the long term health outcomes of whole indigenous communities wherever they live."

OUR SUPPORTERS

COPORATE SUPPORTERS



- Innovation Act
- Commonwealth Youth Forum 2011
- Platinum Speakers
- Canberra Design House
- Eltham World Harmonies Inc
- Toll
- Kelly + Partners Chartered Accounts
- Australia Medical Students Association
- Office for Aboriginal and Torres Strait Islander Health

WE WOULD LIKE TO WELCOME ON BOARD:



THE JOHN & MYRIAM WYLIE FOUNDATION



YOL NJU
POWER

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