



(See, Treat, Prevent) Skin Sores and Scabies



The **SToP** Trial: **See Treat Prevent** skin sores and scabies A healthy skin programme in communities in the Kimberley

Information sheet for parents/carers *Child participation in school skin checks*

Dear Parent/Carer,

My name is Dr Asha Bowen and I am writing to you on behalf of the Telethon Kids Institute. We are conducting a research project called the SToP study that aims to improve skin health in the Kimberley. I would like to invite you and your child to participate in the study. The SToP researchers will work with your community including your family, the clinic and local schools as part of the study. Your child's school is one of 8 schools across the Kimberley that are involved.

Please ask us questions any time

Skin health is a **BIG** problem

Who is doing this project?

Your child's school is participating in this project as part of the SToP study being done by researchers from **Telethon Kids Institute** in partnership with **Kimberley Aboriginal Medical Services (KAMS)** and **WA Country Health Service, Kimberley Region (WACHS– Kimberley)**. The lead investigator is Dr Asha Bowen from Telethon Kids Institute.

What is this project about?



Do you know a lot of our people have got skin sores and scabies?

If kids suffer from these things, they feel bad at school. They need to go to the clinic to get medicine, otherwise they might get very sick. They might get sick kidneys or rheumatic heart.



We need to look after our skin
 We need to look after our kids
 We need to look after our community

We need to work together to
 get rid of skin sores and scabies to make our
 kids and everyone feel better

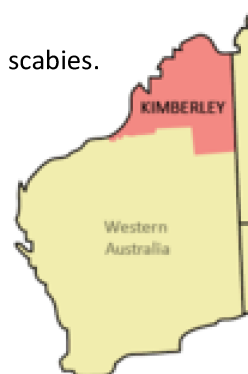
What we would like to do



We want to work together with Aboriginal communities, parents, kids, schools, and health workers to help stop skin sores and scabies. We want to help by doing a project called the SToP study. In the SToP study we want to:

- Check kids’ skin at school 3 times per year for 3 years. If kids have skin sores or scabies we will refer them to clinic to get medicine. Skin checks will take place during normal school time outside of the classroom and take about 5 minutes for each child.
- Train clinic staff on the best ways to treat skin sores and scabies.
- Work with health services and communities to prevent skin sores and scabies.

We will do the SToP study in four groups of communities in the Kimberley. The SToP study will take about three years to do. All throughout the study time, we will be checking the kids’ skin school three times a year in all communities. We do this because this is our way of checking if the study is working.



We are asking permission for your child/children to take part in the SToP study and to check their skin at school.

This means we are asking you if you want to:

Action	Why?
Before we start, we talk to you about the SToP study and we ask you to talk about the SToP study to your child. If you want to take part, we ask you to sign a consent form.	To make sure it’s okay for your child to be involved in the project and that you understand what the project is about.
If you say yes, we will:	

<p>Check your child's skin at school for skin sores and scabies. We will do this 3 times per year, for 3 years. We will check the skin that we can see (head, arms, legs). If your child has skin sores or scabies, we will refer them to the clinic to get medicine. We will also ask your child if they have skin sores or scabies on somewhere else their body. If they say they do, we will refer them to the clinic to get these areas checked.</p> <p>We will also take a skin swab of their skin sore (if they have one) and may take a photo of the skin sore.</p> <p>We will also take a throat swab at the first and last study visits.</p> <p>Ask your child some questions about their health and age, and measure their height and weight.</p>	<p>We want to make sure that kids with skin sores and scabies get medicine so they don't get sick. Checking skin at school helps us to do this, and also helps us know if the SToP study works. If the SToP study works, we hope less kids have skin sores and scabies at the end of the year.</p> <p>We can use photos to show if skin sores are getting better over the year, and because photos may be used in future training and publications.</p> <p>Skin and throat swabs will be sent to a lab to check if there are bacteria that could be causing the skin sores and scabies. We will also store the swabs for future projects (with your permission).</p> <p>We want to know if some kids get more skin sores and scabies than others. The study team and the teacher might help your child with these questions.</p> <p>This <u>won't</u> affect your child's school results.</p>
<p>We would also like to:</p>	
<p>Complete a media consent form.</p>	<p>We will only take photos of your children if you tell us it is ok .</p>

Each time we see your child at school, it will take about 15 minutes to for them to do the skin checks.

Are there any benefits to being in the study?

Yes. Your child will be checked for skin sores and scabies at school and they will be referred to the local clinic for medicine if they need it. These are extra skin checks that might not usually happen at school. Your child will also learn about skin sores and scabies at school with all the other children.

Are there any risks, side effects, discomforts, or inconveniences from being in the study?

If your child has got a skin sore, we will take a skin swab. This might be a bit ticklish for a few seconds but it won't harm your child. When we take throat swabs, this might also be a bit uncomfortable because it touches the back of your throat and your child might gag. Otherwise, there are no risks or harms to you or your child taking part in this study.

What if I say no?

You can say no. It's okay to say no. It's your choice.

You don't have to give permission for your child to do the SToP study. Your decision will not affect your child's school care or results. If you don't want your child to do the SToP study, it means they will not get their skin checked at school, but you can still take them to the clinic to get their skin checked if you are worried about skin sores or scabies. Your child will continue to participate in other regular school activities if you say no to the study.

Can I change my mind?

Yes. If you want to take part, you can also change your mind at any time and stop – just tell us. Any information we collected up until this point will be kept and used in the study.

Who will have access to my information?

Only the clinic staff and study team working can see you and your child's name and information. You and your child's name and personal information will be kept private. This means we won't show it to anyone outside of the study team. We may need to share information about your child only in the situation where there are concerns for your child's health and/or safety.

What happens to the information collected about me?



We only collect information that is needed to do the study. You and your family won't be identified in any way when we share results. All information will be locked up on a computer. The results of this study may be published in scientific journals or presented at scientific or community meetings but we will not use you or your family's names.

All information they collect will be stored on a secure computer but names will not be kept next to that information. No one will be able to match your name to the health information. All electronic information will be kept on the Telethon Kids Institute server and a secure, password-protected online database that can only be accessed by authorised team members. Any paper documents will be stored in a locked cupboard/room that can only be accessed by authorised team members.

Information will be kept for a minimum of 25 years, after which it will be destroyed as per Telethon Kids Institute's Information Retention & Disposal Policy and with authorisation from the lead investigator. Electronic records are digitally destroyed prior to disposal. Paper records are destroyed by shredding.

Will you tell us about the results of the study?

Yes, we will tell you. We will tell everyone about the results. We will talk with communities and participants to tell them about the results and we will provide you with written information about the results too.

Has this project been approved?

All research in Australia involving humans is checked by a group of people called a Human Research Ethics Committee (HREC) to make sure it is safe to do. This study has been checked and approved by the Western Australian Aboriginal Health Ethics Committee (WAAHEC) and Child and Adolescent Health Service (CAHS) HRECs. If you have concerns or complaints about the study you can contact them any time:



- WAAHEC HREC at ethics@ahcwa.org and (08) 9227 1631 or;
- For CAHS HREC, The Executive Director Medical Services, on (08) 6456 2222

How do I know that the people involved in this research have all the appropriate documentation to be working with children?

All persons undertaking research activities on Department sites must complete a Confidential Declaration. Also, under the Working with Children (Criminal Record Checking) Act 2004, people undertaking research that involves contact with children must undergo a Working with Children Check. Evidence that these checks are current for each member of the research team has been provided to the Principal of your school.

What happens next?

If you want to ask any questions about the study, please talk to the study staff. You may also like to contact the Principal Investigator, Dr Asha Bowen or the project team. If you want to take part in the SToP study, we will ask you to sign a consent form. We may also ask your child to sign a consent form.



Dr Asha Bowen



Frieda Mc Loughlin



Rachael Donovan

Dr Asha Bowen, Telethon Kids Institute

Email: asha.bowen@telethonkids.org.au

Frieda Mc Loughlin, Telethon Kids Institute

Email: frieda.mcloughlin@telethonkids.org.au

Rachael Donovan, Telethon Kids Institute

Email: rachael.donovan@telethonkids.org.au



Rahaney Poelina



John Jacky

Rahaney Poelina, Nirrumbuk Environmental Health and Services

Email: Rahaney Poelina rahaney@nirrumbuk.org.au

John Jacky, Telethon Kids Institute

Email: John.jacky@telethonkids.org.au

You can keep this information sheet.

The **SToP** Trial: **See Treat Prevent** skin sores and scabies:
A healthy skin programme in the Kimberley



Consent for parents/guardians - child participation in school skin checks - *This means you can say no*

<i>In saying yes to this study I agree that:</i>		
<ul style="list-style-type: none"> I have read the information sheet or someone has read it to me in a language that I understand and I agree for my child/children to participate in this study. 		
<i>I confirm I am the parent/carer and consent to this study for my child/children:</i>	YES	NO
Check your child/children's skin at school 3 times, for 3 years, for skin sores and scabies. If your child has a skin sore or scabies, we will refer them to the clinic and let you know to take them to the clinic to get medicine.		
Take photographs of skin sores. I agree to these photos being used in future training and publications.		
Take a skin and throat swab.		
I agree that these swabs can be stored for future research studies.		
Ask your child/children questions about them and check their height and weight.		

Information about my child/children - *(Please fill in details for each child)*

Child Full Name	Other Names	Date of Birth	Gender (Male/ Female/ Other)	Aboriginal Torres Strait Islander (Y/N)	Is this your usual community?

Parent /Carer Name: _____

Community Name: _____ House Number/Name: _____

Parent/Carer Signed: _____

SToP Team Name & Signed: _____ Date: (DD/MM/YYYY) _____