

# TAKE ♥ HEART

**The quest to rid Australasia of  
Rheumatic Heart Disease**

Presented by **aspen**foundation



## ***ACTION TOOLKIT***

***A Learning Resource for  
Communities, Schools  
& Health Clinics***

Presented by  
**aspen**foundation



**cure kids**





The Producers express thanks to all of the Project Partners who have made this important public health communications project a reality.



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USE THE DVD TO LAUNCH THE FEATURE FILM FROM THE MAIN MENU



**FEATURE FILM**  
(52 MINUTES, ENGLISH)

Rheumatic Heart Disease, or RHD, is a largely invisible disease that threatens the lives of over 30 million children and young people around the world. *Take Heart: The Quest to Rid the Australasia of Rheumatic Heart Disease* lifts the lid on this life-threatening disease that is 100% preventable.

After viewing the Feature Film, as you move through the rest of this Action Toolkit Guide you can access additional Short Films that accompany each chapter from the Action Toolkit menu on the DVD.

If you lose anything from the Action Toolkit, don't panic, many of the digital resources can be found on the project website [www.TakeHeart.tv](http://www.TakeHeart.tv)

Replacement or additional Action Toolkits and DVDs can also be ordered from the website.



**The Producers acknowledge the Traditional Custodians of the Lands across Australia and we pay our respects to Elders past, present and future.**



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**ABOUT THIS TOOLKIT**

This Action Toolkit Guide is designed as an accompaniment to the DVD *Take Heart: The Quest to Rid Australasia of Rheumatic Heart Disease*, which uses real stories to deliver important health information about Rheumatic Heart Disease (RHD).

This Toolkit is designed to help communities, clinicians, health workers and educators to understand, access and utilise the full suite of resources created for the *Take Heart: Australasia* project. The following icons are included throughout this Action Toolkit Guide directing you to additional resources:



Additional related films are available on the **Take Heart DVD**, under the Action Toolkit menu.



Additional downloadable information or helpful links are available on the project website [\*\*www.TakeHeart.tv\*\*](http://www.TakeHeart.tv)

The following icons identify particular interest areas for communities, health workers and educators:



Community Interest



Health Worker Interest



Educator Interest

For best results, watch the Feature Film first before reading the rest of this Action Toolkit Guide. This Film provides a comprehensive overview of Rheumatic Heart Disease. This foundation will help you make the most of this resource.





***Bupa is proud to be the Outreach Partner of the Take Heart toolkit.***

Australia's first people have amongst the highest rates of Rheumatic Heart Disease (RHD) in the world, despite Rheumatic Heart Disease being 100% preventable.

Providing Australians with access to information and tools such as the Take Heart Action Toolkit is an important step towards beating this disease, and Bupa is proud to be the Outreach Partner of the Take Heart project to make these resources available to your community.

The Take Heart film is an important conversation starter surrounding Rheumatic Heart Disease and this toolkit provides a learning resource for Indigenous communities, schools and health clinics.

Through the stories of young people impacted by RHD, we hope that the film and toolkit provides valuable information to support the health of young people in local communities.

A sore throat, infected skin sores or fever should always be checked at a health clinic. For those living with Rheumatic Heart Disease on a secondary prophylaxis, injections must be on time, every time.

Children and young people are dying unnecessarily. By engaging with your local community and health clinicians we can together beat Rheumatic Heart Disease.

We hope you find the Take Heart Toolkit a useful and knowledgeable tool.

Yours sincerely,

Dr Rob Grenfell  
National Medical Director  
Bupa Australia and New Zealand





***Aspen Foundation proudly presents the Take Heart project.***

Over the past 6 years the Aspen Foundation has focussed its resources on addressing chronic diseases in our Indigenous Communities.

The Foundation and our partners are currently supporting the eradication of Trachoma and Crusted Scabies through a variety of programs.

The prevalence of Rheumatic Heart Disease (RHD) needs to be addressed. When we were approached to join the effort to fight RHD we had no hesitation in supporting this meaningful cause.

As we know Indigenous Australians, Māoris and Pacific Islanders have amongst the highest rates of RHD in the world. Children, young adults and pregnant woman are hardest hit.

We also know that RHD is completely preventable and toolkits such as these will help to educate health professionals and communities to tackle this disease.

Our vision should be nothing short of eradicating RHD from Indigenous communities in Australia.

On behalf of the Aspen Foundation I would like to congratulate all who have worked on the Take Heart Action Toolkit and documentary.

As the conclusion of the Toolkit highlights; in countries as fortunate as Australia and New Zealand, there is no reason that Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) should threaten and damage the lives of any more children, their families and the community.

A handwritten signature in black ink, reading "A Keys".

Amelda Keys  
Chair  
Aspen Foundation





## CHAPTER 1: RHEUMATIC HEART DISEASE IN AUSTRALIA

Australia is the world's 6th largest country by size and has been home to Indigenous Australians for over 40,000 years.

Today, Australia boasts the world's 12th largest economy, the 5th highest per capita income, and the 2nd highest human development index ranking - which means it's considered to be amongst the world's most 'equal' societies.

*Why then, do Australia's First Peoples have amongst the highest rates of a preventable disease in the world?*



### What is Rheumatic Heart Disease?



Rheumatic Heart Disease (RHD) starts as a Strep (Group A Streptococcus) infection from a common sore throat, mainly in children aged 5 – 15.

It can end in open heart surgery, stroke, heart failure or premature death. RHD is a progressive, chronic disease that can be fatal - meaning it progressively gets worse, stays with those who have it for life and can end their lives.

RHD begins as Acute Rheumatic Fever. Children with Rheumatic Fever often shows signs of:

- Sore throat
- Infected skin sores
- Fatigue
- Difficulty standing up
- Fever, and
- Sore joints (especially sore knees, elbows, wrists or shoulders).

When a child or young person starts displaying symptoms like these, or has similar signs, don't delay, get them to the health clinic to get it checked.

If it is a Strep infection, the sooner it is treated with antibiotics, the better off that child will be.

Clinician & health worker modules available at: [www.TakeHeart.tv](http://www.TakeHeart.tv)



***Rheumatic Heart Disease (RHD) is a preventable disease associated with social disadvantage. By working together and closing the gap on Indigenous disadvantage, rates of RHD will be reduced to next to nothing.***





### Available in:

English  
Burrarra  
Yolngu Matha  
Anindilykawa  
Warlpiri  
West Kimberley Kriol  
Pitjantjatjara

### ***This is a health warning.***

Right now, many of our children and young males and females in our community are getting Rheumatic Fever and Rheumatic Heart Disease.

This is serious. Rheumatic Fever can damage our heart.

Watch out for children and young males and females with:

1. Painful joints (like ankle, knees, hip or elbow, wrist, shoulder), and
2. Fever (feeling cold and shivering but when you feel their forehead they feel very hot to touch).

Bring these children and young males and females to the clinic so we can give them medicine.  
This medicine will stop this sickness and prevent heart damage.

What causes Rheumatic Fever?

Rheumatic Fever starts with a sore throat and sometimes with sores on our skin.

One germ called 'Strep' lives in the throat and in skin sores.

When you see pus in skin sores, it means that strep germs are camping there.

They have found a good camping place and are growing and multiplying there.  
Or, if we have a sore throat with pus, the same germ is living there.

These Strep germs get inside our children's body and damage their heart.

Penicillin Medicine kills these strep germs and keeps your heart good.

For people who already have Rheumatic Fever, they need a penicillin needle every 21-28 days.

This medicine will stop Rheumatic Fever coming back.

The medicine only stays in our body for 21-28 days.

It goes all around our body and protects us from the Strep germ.

After 21-28 days, the medicine is used up - finished. Then we need to give another injection.

People with Rheumatic Fever need penicillin in their body all the time to kill any Strep germs.

We can protect their heart by giving this injection.

So to prevent Rheumatic Heart Disease think about Strep germs and how to keep them away:

- Wash your hands to remove Strep riding on them.
- If you've got sores, get treatment and cover them with a bandage.
- If you've got sore throat, get treatment for sore throat quickly.
- Keep your house clean to kill any Strep.

*Important Health Message: Acute Rheumatic Fever written by Alice Mitchell & Bernadette Nethercott for Aboriginal language interpreting.*





## Mr Stan Grant Personal Statement on Rheumatic Heart Disease (RHD)



*“Indigenous people still suffer far more greatly than any other section of the Australian population and Rheumatic Heart Disease is an extraordinary example of this.” ~ Mr Stan Grant*



## Take Heart Trailer

To *Close the Gap*, health care will need to be delivered to at-risk children, adolescents and young people where and when they need it, social housing conditions will have to be improved to reduce overcrowding, and education programs designed to improve understanding of the disease will have to be deployed.



Clearly, we have a problem in this part of the world - the lives of thousands of young people are threatened.

But there's also a solution - this disease is entirely preventable.

So whose problem is this to solve?

Those most at risk?

Those in their community?

Those in the health service?

Those in the public service?

Those in the lab?

Those in power?

Ultimately, if we want to Close the Gap and authentically lay claim to an equal society - then we must view this as everyone's problem.



## **DID YOU KNOW?**



**Over 30 million children and young people are estimated to have Rheumatic Heart Disease (RHD) - World Heart Federation.**

**Indigenous Australians, Māoris and Pacific Islanders have amongst the highest rates of RHD in the world.**

**Children, young adults and pregnant woman are hardest hit.**



## **REMEMBER...**

**Rheumatic Heart Disease (RHD) is 100% preventable.**

**Yet Australia and New Zealand's first people have amongst the highest rates in the world.**

**By working together to rid Australasia of RHD, we can help Close the Gap on Indigenous disadvantage.**

## **TAKE ACTION!**

**TOGETHER WE ARE STRONGER** - Share the *Take Heart Trailer* using the DVD, social media and email, especially with people who have never heard of the disease.



**YOUR VOICE MATTERS** - Be vocal about the issue in your community, amongst your networks and using social media. Follow the project at [www.TakeHeart.tv](http://www.TakeHeart.tv)





## CHAPTER 2: BROOKLYN'S STORY

Brooklyn is a young girl from Darwin. Her family relocated to Darwin from their home in Elcho Island when she was a baby. Brooklyn lives with her parents, 4 sisters and nephew. She loves to sing, dance and run.



When Brooklyn was 6 years old, she was diagnosed with severe Rheumatic Heart Disease after just one episode of Acute Rheumatic Fever.

She spent 3 months in Royal Darwin Hospital under observation to monitor the damage to her heart from Rheumatic Heart Disease.

This was a difficult time for Brooklyn to be away from her family. She was breathless and unable to do the activities she enjoys. She also disliked the injections she needed to have to protect her heart from further damage.

### What is Acute Rheumatic Fever (ARF)?

Acute Rheumatic Fever (ARF) is caused by the Group A Streptococcus bacteria (sometimes called a Strep or GAS infection).

The Streptococcal bacteria, or germs, are highly contagious and spread easily through airborne droplets when someone with the infection in their throat coughs or sneezes, or through sharing food or drinks. Untreated sore throat (Strep Throat) can develop into Acute Rheumatic Fever (ARF).

Another suspected cause of infection is when Strep germs enter the body through infected skin sores, and sometimes through infected scabies - though further research is required to scientifically prove this. Research initiatives are underway to understand this to reduce the burden of RHD.



Acute Rheumatic Fever (ARF) happens when a child's antibodies - the inside hunters that protect the body by getting rid of invaders that may cause harm - destroy the Strep bacteria. The problem is - in some children - these hunters also attack the heart which contain similar looking proteins to those of the invaders.

These attacks can damage some of the heart valves - or doors - and reduce the heart's capacity to pump blood. If this continues without antibiotic medication to stop the attack, it causes permanent damage, usually to the mitral and aortic valves. This permanent damage is known as Rheumatic Heart Disease.



# Heart Repair Surgery

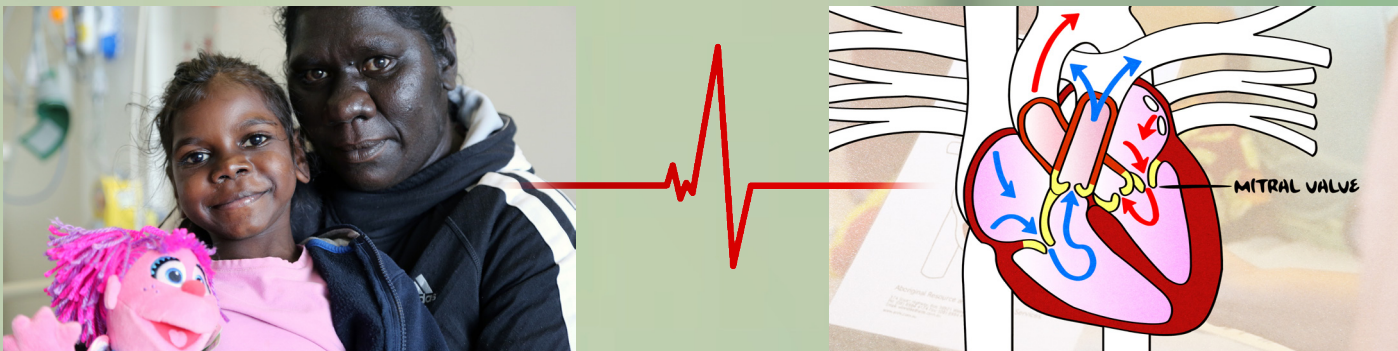


After 3 months under observation, Brooklyn’s heart function has worsened.

Brooklyn and her parents are now facing a diagnosis of Rheumatic Heart Disease (RHD). They are not alone. It is estimated that nearly 2 per cent of all Indigenous Australians are living with RHD.

Brooklyn must now leave Darwin and most of her family far behind - taking the 4 hour flight south to Melbourne. The Royal Children’s Hospital in Melbourne is one of the only hospitals in Australia capable of performing this kind of surgery.

On her 7th birthday, Brooklyn has been accepted for surgery to repair her damaged mitral valve.



Mitral valve repair is an open heart surgery to treat narrowing or leakage of the mitral valve.

The mitral valve is the ‘inflow valve’ for the left side of the heart. Blood flows from the lungs, where it picks up oxygen, and into this door of the heart.

Acute Rheumatic Fever (ARF) can damage the mitral valve, as with Brooklyn, to the point where the valve needs to be repaired by expert surgeons.



**Acute Rheumatic Fever (ARF)  
is caused by the Group A  
Streptococcus bacteria  
(or Strep germs).**



**Staying Well After Surgery**

Thankfully, Brooklyn's mitral valve repair surgery has been successful. She can now do all the things she loves to do including singing, dancing and running.

On her chest, she now carries the scar of her RHD surgery.

To stay safe and well, Brooklyn must have a penicillin injection every 28 days.

This medicine stays in her body and releases slowly over time.

If she is exposed to the Strep germ during this time, the penicillin kills it, preventing any further damage. But she has to stick to the injection program set out by the health clinic doctor.

Just one day late for an injection and she is once again at risk.

Brooklyn dislikes the painful penicillin shots. But her parents understand the importance of the medication and the need to stick to the injection program.



***When more than 2 children share the same bedroom, the chances of Strep infection increase.***



**Healthy Homes Protect Children**

Brooklyn's home can be crowded, particularly when her extended family visits from Elcho Island.

Overcrowding is a known factor contributing to the spread of Strep.

Strep is highly contagious, which means that it spreads easily.

It is important for all families to keep healthy homes, that keep their children safe from infection.

Some simple ways to keep a healthy home are to:

**Healthy Homes Checklist**

- ☒ Get children with sore throats, infected skin sores, sore joints or fever to the health clinic quickly.
- ☒ Make as much space between the children's beds as possible.
- ☒ Keep bedding clean and dry.
- ☒ Keep homes clean and tidy.
- ☒ Wash hands before eating and drinking.





## **Strep: Group A Streptococcal (GAS) Infection**



***"The strep bug is an old bug that we've known about for a long time that causes a variety of illnesses. The ones that most people know about are sore throat. That's the most common bacterial cause of sore throat. I think most people in the world have experienced strep throat."***

**- Associate Professor Andrew Steer**



### **REMEMBER...**

***Acute Rheumatic Fever (ARF) is caused by the Group A Streptococcus bacteria (or Strep germs).***

***Strep is highly contagious, easy to spread through close contact and sharing.***

***Overcrowding is a known factor contributing to the spread of Strep.***

***Strep gets into your body from a sore throat (Strep Throat) or infected skin sores (including Scabies).***

### **TAKE ACTION!**

***GET THE FACTS*** - Print the Rheumatic Fever Fact Sheets and put it up at your Home, School, Health Clinic or Community Centre. **[www.TakeHeart.tv](http://www.TakeHeart.tv)**

***SPREAD THE WORD*** - Watch and share the Group A Streptococcus Short Film using the DVD and social media, especially with families containing a family member on a regular penicillin injection program.





## **CHAPTER 3: LIDDYWOO'S STORY**

Edward, who prefers to be called by his Aboriginal name, Liddywoo, is 15 years old. He too, is suffering from RHD, and has moved from his homeland in Belyuen to Darwin, to receive medical treatment for his condition.

He is unable to do many of the things his friends do, particularly physical activities like running, dancing and playing football. This is because his heart is sick and unable to pump enough blood. This means Liddywoo often feels tired and breathless.



Liddywoo's mother Rosemary is worried about her son. He has already had 2 open heart surgeries.

Each of these surgeries has taken place at the Royal Children's Hospital in Melbourne. As a result, Rosemary and Liddywoo have needed to spend months away from their family in Darwin.

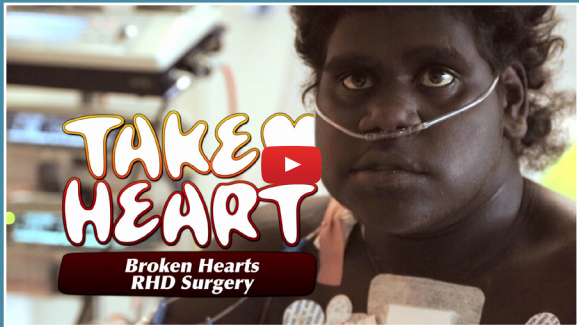
When he was 9, Liddywoo had 3 heart valves repaired. The reason he needed a second operation was because he wasn't able to stay on track with his regular penicillin injections every 28 days.

Between the ages of 13 to 15, Edward was barely able to move around and walk. The only option is to undergo an operation to replace two of his heart valves with mechanical heart valves.

Liddywoo has now started coughing up blood. At this stage, to save Liddywoo's life he must undergo a 3rd operation called mechanical heart valve replacement surgery.

***"If we don't do anything, Edward will die in a matter of weeks, so he has to have his surgery done quickly."***  
**~ Associate Professor Yves d'Udekem**  
**Cardiac Surgeon, Royal Children's Hospital, Melbourne**





Back in Melbourne for his 3rd open heart surgery, Liddywoo’s mitral and aortic heart valves are so damaged, that they can no longer be repaired.

With the new mechanical valves implanted, Liddywoo’s life will be saved but he will need to take daily anti-coagulant tablets, called warfarin, to prevent blood clots forming in the valves.

Liddywoo, his family, friends and health providers must now take extra care to ensure he stays healthy and well.



**LIDDYWOO’S RHD EXPERIENCE**

<i>Days spent in Hospital</i>	=	<b>200+</b>
<i>Days absent from School</i>	=	<b>500+</b>
<i>Days spent Inactive</i>	=	<b>1,000+</b>
<i>Estimated lifetime penicillin injections</i>	=	<b>500+</b>
<i>Estimated lifetime warfarin tablets</i>	=	<b>18,000+</b>
<i>Estimated lifetime cost of Treatment</i>	=	<b>\$2,000,000+</b>





## What is Secondary Prophylaxis?



Thankfully, Liddywoo's mechanical heart valve surgery has been a success. Now, to stay alive and well, Liddywoo also needs to continue getting penicillin injections every 28 days. This treatment is called Secondary Prophylaxis.

Secondary Prophylaxis involves the continuous administration of a specific antibiotic penicillin to patients with a previous attack of Rheumatic Fever, or well-documented RHD. An injection every 21-28 days allows penicillin to be released slowly over time to prevent further damage that could be caused by another Strep infection and the resulting damage to the heart valves.

It is vital for young people like Liddywoo to stay on track in getting their injections on time, every time. Just one day late and they are again at risk.

***For those on a regular  
injection program:  
To stay alive and well.  
Get injections  
ON TIME, EVERY TIME.***







## Take Heart App



A free App has been developed in collaboration with the Laynhapuy Homelands.

This App is designed to help people who require regular Secondary Prophylaxis (penicillin injections) to protect themselves from Acute Rheumatic Fever and RHD.

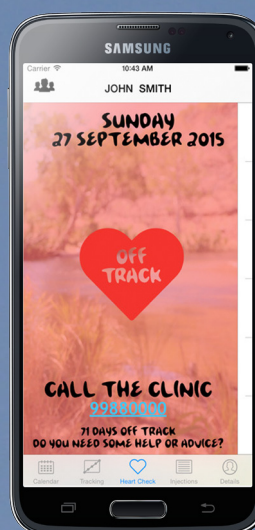
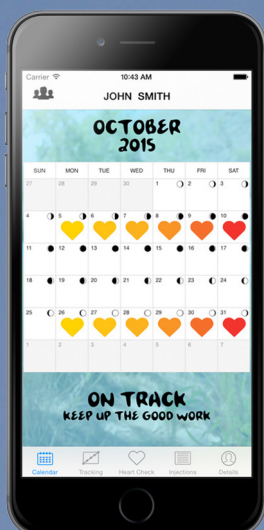
This App is also useful for family, friends, co-workers, health workers and clinic staff caring for people who require regular Secondary Prophylaxis.

This App contains several, easy-to-use tools and alerts designed to help people stay on track with their regular 28 or 21 day injection programs including:

- Daily push alerts to remind users that injections are due in the week leading up to the next injection
- Calendar function to clearly see when future injections are due
- Tracking tools to monitor how many days the user has been on-track and off-track
- A quick-glance Heart Check interface to see if you are currently on-track or off-track
- One-press facility to call the user's registered health clinic
- Ability to add user and clinic details and to keep track of past injections
- Ability to keep track of multiple users on one device



Once the App is downloaded, it does not require ongoing cellular network or Internet access to function.



## REMEMBER...

**Secondary Prophylaxis is the regular injection program that keeps people with Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) safe and well.**

**RHD Surgery can be caused by not keeping on track with Secondary Prophylaxis (failure to receive regular injections on time, every time).**

## TAKE ACTION!

**MANAGE YOUR INJECTIONS** - Download the free Take Heart Smart Phone App for Apple or Android to help you or someone you know stay on track with their 21-28 day injections. Instructions on how to download and use the App are available at [www.TakeHeart.tv](http://www.TakeHeart.tv)



**SPREAD THE WORD** - Share the *Broken Hearts: RHD Surgery* short film using the DVD and social media, especially with people on a regular penicillin injection program.





## **CHAPTER 4:** **CARLISA'S STORY**

Carlisa is 14 years old.

She has had 4 open heart surgeries - the last to implant a mechanical valve that audibly clicks as it pumps blood through her body.



Today, Carlisa is getting her blood tested to check if it's too thin or too thick.

This is to determine whether she needs more or less of the anticoagulant medicine warfarin.

She must take warfarin every day for the rest of her life to prevent blood clots forming on her mechanical valve.

If blood clots form on her mechanical valve, Carlisa could have a stroke - where blood is blocked from going to the brain and the brain is damaged.



### ***Where's your "Feeling Better" Place?***

A health clinic is a feeling better place.

Carlisa's health clinic is in the town of Katherine, around 300 kilometres south of Darwin.

Medical centres like this one often service vast tracts of northern and central Australia.

Here they do blood tests, penicillin injections, and educate patients about RHD.

Carlisa lives 60 kilometres north of Katherine, in the remote community of Werenbun, overlooking the Nitmiluk National Park (near Edith Falls).

The responsibility falls on Carlisa's father to bring her to the clinic.

This is often difficult, due to the availability of reliable vehicles in her community. A bus is sent to Werenbun each Tuesday by one health service to assist with transport.

No clinic is officially required to service Werenbun.







One of the greatest challenges in closing the gap on Indigenous disadvantage is faced by remote communities like Carlisa's, where social services are even less accessible.

Unfortunately, difficulty getting to the health clinic in Katherine means Carlisa has been unable to keep on track with her essential medicines.

And Carlisa knows full well that the stakes involved in her keeping on track in this regard are literally life-and-death.

*"My uncle died from Rheumatic Heart Disease, and my other uncle died from it too, and my mum, and my cousin-sister,"* reflects Carlisa.

To stay alive and well, Carlisa will need rapid and responsive health services available to her for the rest of her life.

### **WHAT IS A STROKE?**

***A stroke happens when blood clots form, then blood is blocked from going to the brain and the brain is damaged.***



***"Sometimes when I think about it, having a stroke, it sounds really scary and I don't want to take a stroke because I'm too young to die."***





## Staying on Track with Secondary Prophylaxis



When Brooklyn was 6 years old, she was diagnosed with severe Rheumatic Heart Disease (RHD) after just one case of Acute Rheumatic Fever (ARF).

She spent 3 months in Royal Darwin Hospital under observation to monitor the damage to her heart from Rheumatic Heart Disease (RHD).

This was a difficult time for Brooklyn to be away from her family. She was breathless and unable to do the activities she enjoys.

Thankfully, most young people with Rheumatic Heart Disease won't need a mechanical heart valve replacement, which means they also won't need to take warfarin everyday.

For most young people with RHD, like Trenton from Tiwi Islands (shown above), the important thing is to stay on track with Secondary Prophylaxis (regular penicillin injections).

Young people on a regular injection program who get their injections on time, every time will keep themselves safe from stroke, permanent disability, heart failure and premature death.

***“We know that the penicillin injections, if they’re delivered on time, then essentially there’s no chance that Rheumatic Fever will come back. It’s a very good treatment.” ~ Dr Bo Remenyi***







Before her disease got worse, Carlisa showed signs, or symptoms. First she got sick - she had a fever - which is when she was feeling cold and shivering, but her forehead was hot to touch. She also felt tired and breathless. Her legs and knees started to swell up and her joints were sore. She also noticed that her heart was racing.

When a child or young person starts displaying symptoms like these, or has similar signs and a sore throat, don't delay, get them to the Health Clinic to get it checked.

If it is a Strep infection, the sooner it is treated with antibiotics, the better off that child will be.

### **REMEMBER...**

***Children with Rheumatic Fever often have a fever, sore joints (have trouble standing up), feel tired and have a sore throat or infected skin sores.***

***If a child has these signs - or symptoms - don't delay, get them to the health clinic to check.***

***For those on a regular injection program: To stay alive and well. Get injections on time, every time.***

### **TAKE ACTION!**

**WHERE IS YOUR HEALTH CLINIC** - Look up and save the name of your Health Clinic, its phone number, your Doctor or Aboriginal Health Practitioner and their emergency phone number. Free diagnosis calculator App available at: [www.TakeHeart.tv](http://www.TakeHeart.tv)



**SPREAD THE WORD** - Share the *Staying On Track with Secondary Prophylaxis Short Film* using the DVD and social media, especially with families containing a family member on a regular penicillin Injection program.







In New Zealand, Rheumatic Heart Disease is largely confined to the upper North Island. The Indigenous Māori and Pacific Islander populations are predominantly affected. Together, this group comprises almost one third of New Zealand’s youth.

As part of the new results-driven focus of the public service, the Government of New Zealand has committed to reducing the incidence of Rheumatic Fever.

The outcome is a new cross-government prevention programme designed to ‘Stop Sore Throats Hurting Hearts’.

***We’re being Heroes...***

At Polyfest - a youth festival celebrating New Zealand’s Islander culture - there is an information tent and a youth ambassador group working to raise awareness about rheumatic fever.

*“My name is Melesiu Ula, and I’m 17 years old. I am Tongan, full Tongan.”*

*“Our ambassador group is trying to find an easier way to explain to little kids what Rheumatic Fever is. So we’re trying to get it out there that Rheumatic Fever is caused by a sore throat, so we try to make videos and everything we can do to help more kids not get Rheumatic Fever.”*

*“So yeah, we’re being heroes.”*

***“Now I’m 17, I don’t want what happened to me to happen to other kids.” ~ Melesiu***





# Melesiu's Story



*“When I was around ten years old I tried to stand up to go get something but my legs just fell to the ground. I just thought it was nothing.”*

*“The next morning I had a really bad sore throat and I thought it was weird, that these two things are happening. So we went down to Starship Hospital and my dad carried me down and told them what happened.”*

Starship Children's Health is one of New Zealand's leading specialist child health care services. The nurses there immediately took action and Melesiu was kept in the hospital under observation for 2 months.

Like Brooklyn's parents, Melesiu's family had no prior knowledge of Rheumatic Fever.

When Melesiu contracted Rheumatic Fever her family lived in a crowded two-bedroom house.

*“8 people lived in this house,”* recalls Melesiu's mother Veisia. *“And this is where Melesiu got the Rheumatic Fever. We had four girls in one bedroom, me and my husband in the other bedroom, and the boys in the lounge.”*

Poor housing conditions and overcrowding dramatically increase the transmission of Strep.

The rates of Rheumatic Fever in crowded households are almost twice as high as households containing 2 or fewer people per bedroom.







## Rheumatic Fever Prevention in New Zealand



New Zealand's prevention program aims to reduce Acute Rheumatic Fever by two-thirds in its first phase.

A key strategy of the program is to target at-risk children directly, with education to increase their understanding of the Strep bacteria and the symptoms of Rheumatic Fever.

New Zealand's Prevention Program is designed to catch cases of Strep Throat early and treat children rapidly to prevent Acute Rheumatic Fever from developing in the first instance. Another part of the Prevention Program is the Healthy Homes initiative.

Housing conditions are assessed to reduce the likelihood of an occurrence of recurrence of Rheumatic Fever within a household.



*Preventing Rheumatic Fever*

***"I went hunting with my brother and I was just tired and I just couldn't walk around like normal.***

***So I just went and sat in the truck and after that for a bit I didn't feel right and I went to the doctor" ~ Taame***





**Does Rheumatic Heart Disease run in families?**



Acute Rheumatic Fever (ARF) and subsequent Rheumatic Heart Disease (RHD) is close to home for Taame - his mother had it and his sister is suspected of having it.

Having close relatives with Rheumatic Fever can fuel the idea that family members are destined to contract the disease no matter what precautions they take.

*“Not all of this is about genetics,” states Dr Lance O’Sullivan.*

*“Not all of this is about the fact that: ‘Hey, if mum’s got it, it’s predetermined that I’m going to get it.’”*

*“We’re really trying hard to break that myth down, that actually a lot of these people are sharing the same risk factors, perhaps the overcrowding, perhaps the awareness of sore throats perhaps not being as high as we’d like and not considered to be important enough to take kids to doctors.”*

**Teaching school kids about Rheumatic Fever and RHD**

To combat this lack of awareness, the MOKO Program delivers health care to 10 schools in New Zealand’s Northland. Teams of health workers visit the schools 3 times a week, developing close bonds with the students, checking for sore throats and sharing key health information.

And the kids are responding.

*“The children come to them and say: ‘I’ve got a sore throat, I need a throat swab,’”* reflects Dr Lance O’Sullivan.

*“Children are sponges, they learn so quickly about the fact that: ‘Hey look, sore throats are important, get them checked, and if I’m on antibiotics, complete them.’”*



**PREVENTION WORKS - New Zealand’s prevention programme has generated a significant reduction in the incidence of Rheumatic Fever**

**REMEMBER...**

**A sore throat can be swabbed and tested to check whether it is a Strep infection.**

**Children with Acute Rheumatic Fever need to be kept in hospital under observation to monitor the condition of their heart valves.**

**Crowded homes and sleeping quarters increase the chances of Strep being passed from one child to another in the same house.**

**TAKE ACTION!**

**FAMILY ACTION -** Download or print the Rheumatic Fever Family Guide providing an easy-to-read guide to what your family & community needs to know about Rheumatic Fever.

**WALLET CARD -** Print out the wallet card to remind you what to ask the Doctor, Nurse or Local Health Practitioner about on your next visit.







## CHAPTER 6: RHD PREGNANCY STORY

When Justice's mother fell pregnant, complications related to her Rheumatic Heart Disease (RHD) caused Justice to be born 16 weeks premature.

She then stayed in hospital for the first 8 months of her life. As baby Justice became stronger, her mother's health declined.

*"She's had not just one stroke but two strokes. She now can't walk or eat, she can't communicate with us. Her right side works, but her left side just doesn't work."*

***"It's pretty tragic, my mum was diagnosed with Rheumatic Fever when she was young."***

***"They didn't catch it early enough and she ended up having to get open heart surgery and her valves replaced" ~ Justice***







# Rheumatic Heart Disease in Pregnancy



During pregnancy, it's essential that women with Rheumatic Heart Disease receive any prescribed Secondary Prophylaxis (usually penicillin injections every 21-28 days).

This treatment is safe and will not harm the baby in any way.

*"The big thing about Acute Rheumatic Fever is to think of it because it's hard to diagnose. Often there are only vague presentations but typically there's a fever and joint pain."*

## Are females at higher risk?

Up to twice as many females are diagnosed with Rheumatic Heart Disease (RHD) than males.

Indigenous Australian, Māori and Pacific Islander girls and young women are at the greatest risk of getting Rheumatic Fever and Rheumatic Heart Disease.

Pregnancy is a particularly critical time.

*"One of the big issues is that it might not be diagnosed,"* explains Dr Jessie Johnston.

*"A young woman might be pregnant and no-one knows she has underlying Rheumatic Heart Disease."*

The risk comes from the fact that pregnancy places an increased strain on the heart. The work that the heart has to do increases by 30-50%.

*"The heart has to work extra hard to pump blood around the body in the pregnant state."*

A pregnant woman with Rheumatic Heart Disease (RHD) should visit a cardiologist (heart doctor) before 20 weeks and be followed carefully through the pregnancy. This will give the best chance for mother and baby to have a safe and healthy pregnancy.

***"We aim for early diagnosis so that the pregnancy can be managed safely." ~ Dr Jessie Johnston***

## REMEMBER...

***Girls are almost twice as likely to get RHD as boys.***

***Women are at higher risk during pregnancy because the heart of a woman carrying a baby is working harder than normal.***

***Pregnant women who could have RHD should get checked at the clinic as early in the pregnancy as possible.***

## TAKE ACTION!

**SPREAD THE WORD** - Share the *Rheumatic Heart Disease in Pregnancy Short Film* using the DVD and social media, especially with women of Indigenous Australian, Māori and Pacific Island origin who have recently fallen pregnant.

**KNOW HOW TO RECOGNISE IT** - Access professional education modules and educational resources about RHD in pregnancy.





## CHAPTER 7: RHD RESEARCH STORY

Further research is vital to understanding the most effective methods of preventing Rheumatic Fever and Rheumatic Heart Disease.

*“If you look at Melbourne in the 1930s white, Caucasian children were filling the wards with Rheumatic Fever and that’s all gone away,”* reflects Associate Professor Nigel Wilson at Starship Hospital in New Zealand.

*“It just happens at the moment in New Zealand, its Māori and Pacific people who are getting the Rheumatic Fever, so there’s probably something in the human genome that makes someone at risk but it’s probably the social, living conditions that are the bigger factor than the genetic factor.”*

*“I think we can win, because we know what causes Rheumatic Fever - it’s Group A Streptococcus. If we could eliminate Group A Streptococcus there would be no Rheumatic Fever, but how we get there we haven’t yet answered.”*

## Quest for the Holy Grail: RHD Vaccine



The so-called Holy Grail of RHD prevention is a Group A Strep vaccine. But this dream is proving difficult to realise.

*“One of the things that makes Streptococcus very difficult to make a vaccine against is that there are hundreds of different strains of Streptococcus,”* explains Professor Michael Good.

*“So the individual can be exposed to one strain and they’ll develop immunity to that strain but then is totally susceptible to another strain they might encounter the following week or month. Therefore because there are so many different strains, it takes a long while to develop immunity to all of them.”*

As a result, the passage of a safe vaccine to market, is likely to be many years away yet.

**A Group A Strep vaccine would prevent the serious health damage caused by Rheumatic Heart Disease.**







## End Rheumatic Heart Disease (RHD)



RHD is a global issue.

Learn more by watching this film which screened at a United Nation's General Assembly event.



### REMEMBER...

*A vaccine is an injection that protects people from disease.*

*A Group A Strep vaccine keeping children safe from Acute Rheumatic Fever and Rheumatic Heart Disease is not available yet, but it might be in the future.*

*Over 30 million people are estimated to have RHD in the world today.*

### TAKE ACTION!

**SPREAD THE WORD** - Share the *Quest for the Holy Grail: RHD Vaccine Short Film* using the DVD and social media, particularly with those involved in vaccine research & development.

**STAY TUNED** - Sign Up to RHD Australia's *Murmur Newsletter* to stay up-to-date about Rheumatic Fever & Rheumatic Heart Disease news.





# CONCLUSION

In countries as fortunate as Australia and New Zealand, there is no reason that Rheumatic Fever and Rheumatic Heart Disease should threaten and damage the lives of any more children, their families and communities. To rid Australasia of Rheumatic Heart Disease we need to work together. The key take-home messages are:

1. Rheumatic Heart Disease (RHD) is 100% Preventable.
2. Indigenous Australians, Māoris & Pacific islanders have amongst the highest rates of Rheumatic Heart Disease (RHD) in the world.
3. Children, young adults and pregnant women are most vulnerable.
4. If a child you know has:  
Sore Throat  
Infected Skin Sores  
Sore Joints  
or  
Fever  
Don't Delay. Go to the Health Clinic to Check It.
5. For those on a regular Injection Program:  
To Stay Alive and Well...  
Get Injections on time, every time.
6. Pregnant women should be checked for undiagnosed Rheumatic Heart Disease.

Take Control. Learn to identify and prevent Rheumatic Heart Disease visit [www.TakeHeart.tv](http://www.TakeHeart.tv)



## Frequently Asked Questions

**Q: How do you get Rheumatic Heart Disease (RHD)?**

A: It starts as a common bacterial infection (Group A Streptococcus) in children 5-15 years of age, and if left untreated, can lead to Acute Rheumatic Fever (ARF) and the permanent heart damage known as Rheumatic Heart Disease (RHD) which can lead to open heart surgery, permanent disability, heart failure, stroke and premature death.

**Q: How do you prevent Rheumatic Heart Disease?**

A: Get symptomatic children checked at the health clinic quickly and strictly maintain the prescribed treatment program.

**Q: What risk factors are related to Rheumatic Heart Disease?**

A: Overcrowding and social disadvantage increase the risk.

**Q: How can medical services help reduce the prevalence of Rheumatic Heart Disease?**

A: Early diagnosis of Acute Rheumatic Fever and access to relevant medical services for at-risk communities.



## **CREDITS**

Created & Produced by



Made Possible Thanks to the Support of



Health & Care  
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Alice Mitchell PhD  
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Associate Professor Andrew Steer  
Philip Hearnden  
Bupa  
RHD Australia

Special Thanks to  
Bupa  
Aspen Foundation  
Snow Foundation  
National Heart Foundation of Australia  
The Cardiac Society of Australia & New Zealand  
Cure Kids  
World Heart Federation  
NT Cardiac  
RHD Australia  
Australasian Maternity Outcomes Surveillance System  
New Zealand Ministry of Health



What disease starts with a sore throat, or infected skin sores in children, and if left untreated can advance to open heart surgery, permanent disability, stroke and premature death?

Rheumatic Heart Disease, or RHD, is a largely invisible disease that threatens the lives of over 30 million children and young people around the world.

**Take Heart: The Quest to Rid the World of Rheumatic Heart Disease** lifts the lid on this life-threatening disease that is 100% preventable.

This powerful and provocative film is the first in a global series that focuses on Australasia - Australia, New Zealand and the South Pacific.

The first peoples of this region - Indigenous Australians, New Zealand Māoris and Pacific Islanders - have among the highest rates of Rheumatic Heart Disease in the world.

While Australia and New Zealand are classified as among the most wealthy and equal societies in the world, this epidemic highlights the gap between Indigenous and non-Indigenous Australasians.

Take Heart provides a first hand account that explores how we can close this gap and prevent more children being struck down by this completely preventable disease.

DVD contains the one hour feature film and 13 short films. For best results, watch the Feature Film first before reading the rest of this Action Toolkit Guide. This Film provides a comprehensive overview of Rheumatic Heart Disease. This foundation will help you make the most of this resource.



This Action Toolkit Guide is designed as an accompaniment to the DVD **Take Heart: The Quest to Rid Australasia of Rheumatic Heart Disease**, which uses real stories to deliver important health information about Rheumatic Heart Disease (RHD).



This Toolkit is designed to help communities, clinicians, health workers and educators to understand, access and utilise the full suite of resources created for the *Take Heart: Australasia* project.