National rheumatic fever strategy
The role of RHDAustralia

RHDA seminar series 2014

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Streptococcus pyogenes bacteria, Pappenheim’s stain
Welcome

- Housekeeping
- Speakers and question time
- Acknowledgements
- Evaluations
- CPD points - pick up certificates or please register your email address
QUICK QUIZ

Who:

• Lives or works remotely?
• Has seen a case of ARF?
• Has given a shot of LA bicillin?
• Knows how to prevent RHD?
• Knows how/whom to refer to?
• Is aware of the National guidelines?
• Has downloaded the App?
• Has subscribed to Murmur and the online FORUM
What is Acute Rheumatic Fever (ARF)?

ARF is an illness caused by a reaction to a bacterial infection with group A Streptococcus (GAS) which can:

- affect the heart, joints, brain and skin
- cause ongoing heart damage leading to Rheumatic Heart Disease (RHD)
- cause joint pain
- lead to hospitalisation
- be prevented

GAS [we can’t see them]
Sore Throat / Skin Sores
Rheumatic Fever
What is Rheumatic Heart Disease (RHD)?

Rheumatic Heart Disease is damage to the heart after episodes of Acute Rheumatic Fever (ARF)

- heart valves are stretched and may be scarred
- blood can't flow properly
- more heart valve damage with more ARF

Rheumatic fever often comes back many times
Sickness builds up and heart valves leak
Heart becomes weak. Bad health and early death
The NT has the highest rate of ARF in Australia with 58% of cases occurring in 5-14 year olds. In the NT rate is 26 times higher in indigenous vs non-indigenous children.
5 fast facts

• Mostly affects children 6-14 years of age & majority are female
• Caused by upper respiratory GAS infection (or skin infections)
• RHD affects 15.6 to 19.6 million people worldwide & causes 233,000 to 492,000 deaths each year.
• Timely diagnosis of an initial ARF episode and subsequent use of antibiotic prophylaxis is the best method of preventing RHD.
• ARF is entirely preventable - ie address the risk factors
The impact
Case discussions

Liddywoo

Brooklyn

Trenton

Carlisa
Brooklyn’s story

- 7 year old girl
- First episode of ARF at age 6 - Jun 2013
- Presentation with polyarthritis, fever, SOB
- Echo in June 2013 - severe RHD, severe mitral regurgitation, severely dilated heart

Social circumstances:
- Country - Elcho island
- Family relocated to Darwin
- 2 adults and 9 children in household
Brooklyn’s story:

Jun 2013
- Diagnosis and hospitalisation in Darwin. Treatment with bed-rest, steroids, penicillin - improvement
- Rebound of ARF
- Progression of RHD, severe pulmonary hypertension, very dilated heart
- On birthday - Brooklyn accepted for cardiac surgery
- 19th of Sept 2013 - Cardiac surgery, mitral valve repair - Melbourne RCH
- Return from cardiac surgery to Darwin
- Persistence of Acute Rheumatic fever
- Discharge from Hospital
- Weekly cardiology review

Aug 2013

Sept 2013

Oct 2013

Late Oct 2013

Courtesy Bo Remenyi
What could have been done to prevent severe RHD?

1. Improve living conditions / social determinates of health
   • Education
   • Housing

2. Treatment of sore throat, skin sore
   • How can we make patient experience better / more acceptable

3. No chance for secondary prophylaxis to prevent heart disease
• Family highly accepting, compliant and supportive with doctors orders

• Brooklyn - on “protest”

• Family (8 kids at home), mother away from home for 4 months whilst Brooklyn in hospital

Protest, despair, detachment

James Robertson (1911-1988)
Psycho-analyst
Tavistock Clinic
• Dependent on compliance to secondary prophylaxis
• Dependent on prevention of recurrence of ARF
• Surgery is NOT a cure for RHD

Survival following isolated mitral valve repair
World Journal of Paediatric Cardiology and Cardiac Surgery 2013
RHEUMATIC HEART DISEASE (RHD) 
NEGLECTED NCD OF POVERTY

Rheumatic heart disease is a sentinel condition of poverty and of health inequality; its persistence marks the failure of our health systems to address the NCDs of the poor.

Professor Bongani Mayosi | South Africa
Doctors call for countries to step up the fight against rheumatic heart disease

Soumyadeep Bhaumik

Kolkata

Greater efforts are needed to prevent rheumatic heart disease (RHD), a meeting at the World Health Assembly was told last week.

Largely eradicated in wealthy countries as a result of effective treatment of its cause, rheumatic fever, RHD remains the commonest acquired heart disease in children in the developing world—"a disease of poverty that kills children, adolescents, and young people in their most productive years," said K Srinath Reddy, president of the World Heart Federation.

RHD is estimated to cause one death every two minutes, but research interest and funding have diminished since the ending of the Global Programme on rheumatic fever and RHD in 2001.1 Academic publications on the subject have declined by two thirds since the 1970s, and just 0.1% of global health research funding for neglected diseases was targeted at rheumatic fever between 2007 and 2012. Total spending in 2010 was $1.7m (£1.1m; €1.3m), itself a 42% decline compared with the previous year, said Reddy.

The meeting held at the assembly—attended by health officials from countries including New Zealand, South Africa, Australia, Fiji, and Rwanda—was designed to reawaken interest and ensure that control of rheumatic fever and RHD should become an integral part of national health planning.

"RHD control programmes are cost effective," Reddy said. "Today only a handful of countries, or regions within countries, have adopted these programmes. As member states consider the first global action plan on non-communicable diseases [NCDs], we urge countries where RHD is prevalent to consider integrating plans to tackle this devastating disease into national NCD plans."

The federation estimates that RHD kills between 233 000 and 468 000 people every year, and that 282 000 new cases are diagnosed each year. In children aged 5-14, prevalence is more than five times higher in sub-Saharan Africa and three times higher in the Pacific and indigenous populations of New Zealand and Australia than in wealthy populations. In the settings where RHD is more prevalent, up to 12.5% of people who develop the disease are at risk of dying each year.

RHD is preventable through cost interventions delivered by basic health services, such as securing universal access to benzathine penicillin G. Used to treat streptococcal infections in the throat, the antibiotic prevents rheumatic fever and hence RHD.

The World Heart Federation has also called for improved planning and training, and is encouraging the development of a group A β haemolytic streptococcal vaccine. The federation has launched a campaign, 25x25x25, calling for action to reduce RHD mortality by 25% by the year 2025, for individuals younger than 25.

Reddy told the BMJ that improved access to benzathine penicillin G would require establishing a reliable supply, developing international manufacturing guidelines and methods to monitor quality, and developing innovative methods of delivery, such as implants.

In addition, he said, efforts should be made to establish a reliable and affordable supply of World Health Organization listed, essential cardiac medication for tertiary prevention, and to encourage clinical trials and license anticoagulant drugs for valvular disease that do not require therapeutic monitoring.

A position statement on an effective polyvalent vaccine against streptococci by the Decade of Vaccine Collaboration is due for publication in 2013, he added.


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ACUTE MODEL VS CHRONIC MODEL

Primary healthcare model - 1978 WHO Alma Ata declaration
Social approach to health founded on human rights framework
Based on economic and social justice
Affordable, accessible, appropriate
Considers culture, environment, ethnicity

ACUTE
• Acute onset
• Single cause
• Accurate prognosis
• Short-term Rx
• Cure likely

CHRONIC
• Gradual onset
• Multiple causes
• Uncertain prognosis
• Lifelong duration
• Cure usually impossible
SOCIAL DETERMINANTS OF HEALTH INCLUDE:

- Stress
- Social exclusion
- Unemployment
- Addiction
- Social gradients (shorter life expectancy, the poorer you are > disease risk)

- Availability of healthy food
- Availability of healthy transportation
- Social support networks
- Early childhood development
PRIMORDIAL PREVENTION of PYODERMA

- Healthy housing
- Education
- Hygiene
- Early detection & treatment of skin sores
- Scabies control
TOWARD CLOSING THE GAP

2018
HALVING THE GAP IN MORTALITY RATES FOR INDIGENOUS CHILDREN UNDER FIVE WITHIN A DECADE

2033
CLOSING THE LIFE EXPECTANCY GAP WITHIN A GENERATION

Making Tracks
toward closing the gap in health outcomes for Indigenous Queenslanders by 2033
Policy and Accountability Framework
FRAMEWORK INCLUDES

- Partnership
- Cultural respect
- Indigenous health is everyone's business
- Holistic health
- Community control of PH services
- Accountability

- Service delivery & investment
- Meaningful consultation
- Identification of effective delivery mechanisms
PRIMARY HEALTHCARE

Working in indigenous communities challenges all these concepts

Despite significant changes in health policy, funding and identification of issues gap may be widening rather than closing
## RISK FACTORS & CAUSE of DEATH

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>Per cent</th>
<th>Rate per 100,000</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Indig</td>
<td>Non-Indig Qld, WA, SA</td>
<td>Indig and NT</td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>19.9</td>
<td>21.1</td>
<td>163.2</td>
</tr>
<tr>
<td>Cancer</td>
<td>13.3</td>
<td>35.9</td>
<td>120.3</td>
</tr>
<tr>
<td>Diabetes</td>
<td>11.1</td>
<td>3.2</td>
<td>104.7</td>
</tr>
<tr>
<td>Suicide</td>
<td>7.7</td>
<td>6.9</td>
<td>27.2</td>
</tr>
<tr>
<td>Road traffic injuries</td>
<td>6.5</td>
<td>4.9</td>
<td>25.9</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>4.5</td>
<td>6.0</td>
<td>40.6</td>
</tr>
<tr>
<td>Alcohol related disease</td>
<td>6.1</td>
<td>2.4</td>
<td>37.6</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>4.2</td>
<td>5.0</td>
<td>45.0</td>
</tr>
<tr>
<td>Selected invasive bacterial and protozoal infections</td>
<td>4.8</td>
<td>2.0</td>
<td>30.7</td>
</tr>
<tr>
<td>Nephritis and nephrosis</td>
<td>3.2</td>
<td>0.8</td>
<td>28.0</td>
</tr>
<tr>
<td>Violence</td>
<td>3.0</td>
<td>0.6</td>
<td>11.6</td>
</tr>
<tr>
<td>Birth defects</td>
<td>2.6</td>
<td>1.6</td>
<td>6.5</td>
</tr>
<tr>
<td>Rheumatic and other valvular heart disease</td>
<td>1.8</td>
<td>0.3</td>
<td>10.2</td>
</tr>
<tr>
<td>Other</td>
<td>11.3</td>
<td>9.3</td>
<td>58.6</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>710.1</td>
</tr>
</tbody>
</table>

*Source: AIHW analysis of National Mortality Database in AIHW, 2006.*
RISK FACTORS

ADDRESSING RISK FACTORS

• Smoking rates
• Rates of risky alcohol consumption
• Rates of decreased tooth decay
• Levels of activity and nutrition
• Rates of sexually transmissible infections
• Numbers of people living in overcrowded and/or substandard housing

MANAGING ILLNESS BETTER

• Life expectancy and HALE
• Better detection (adult health checks)
• Less hospitalisation for cardio-vascular & respiratory diseases, diabetes, cancers and mental illness.
• Better Health Services
• Number of care plans
• Discharge against advice
• Indigenous identification
• Access to health services.
WHAT ARE WE MISSING?

- Refugee population
- Pacific Islander/Maori population
- Not nationally notifiable
- NSW has highest number of indigenous people - 31% vs 30% but there is no register
- Rates of hospitalisation:
  - NT 86/100,000
  - WA 12/100,000
  - Qld 15/100,000
  - Other states?
- Reliable death data?
- Survival time post surgery?
- Economic burden ($ and QALYs)
RHDAUST BACKGROUND

• Based at Menzies in Darwin, NCU established in 2009 to support control of RHD in Australia
• Funded under DoHA Rheumatic Fever Strategy, RHDAustralia until June 2015
• Partners include: Baker IDI, JCU, National Heart Foundation, SAMRHI, Telethon

OVERALL PROGRAM AIM
To reduce death and disability from ARF/RHD in Australian Aboriginal and Torres Strait Islander people by:

• Supporting RHD jurisdictional programs
• Establishing a data collection & reporting system
• Disseminating evidence based practice guidelines
• Increasing community awareness of ARF/RHD & prevention
PROVIDING SUPPORT TO RHD CONTROL PROGRAMS

- Develop high quality education and training resources
- Assist with data interpretation and surveillance reports
- Advice and support on resource allocation and program planning
- Technical advice relating to clinical aspects of service delivery
- Participate in governance committees (steering committees, advisory groups)
- Establishing a national data collection & reporting system
The Guidelines

- New recommended management for Probable ARF
- New algorithm for Management of Probable ARF
- Expanded discussion around short-course antibiotics for treatment of ARF

Quick reference guides

1. Primary prevention of ARF
2. Diagnosis of ARF
3. Management of ARF
4. Secondary prevention of ARF
5. Management of RHD
6. RHD in pregnancy
7. RHD control programs

Find the guideline on the RHDA website homepage here:
SMART PHONE APPS


For more information visit www.rhdaustralia.com.au

Tap Here to read the full disclaimer detailed
EDUCATION & TRAINING RESOURCES

CLINICAL & COMMUNITY
Develop best practice standardised resources
• 6 self paced clinical education modules
• Presentation materials
• Posters, pamphlets, electronic audio and visual media, etc
INCREASING COMMUNITY AWARENESS

- Working with communities to increase awareness
- Raising awareness through media outlets including Indigenous media outlets
- Website development
- E-newsletters and other electronic communications
- Facilitate national conferences and workshops
### CURRENT RHD PROJECTS IN NT & BEYOND

<table>
<thead>
<tr>
<th>Project</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>RHDAustralia</strong></td>
<td>RHDAustralia works with Rheumatic Heart Disease control programs and other partners throughout Australia to reduce death and disability from this disease among Aboriginal and Torres Strait Islander people.</td>
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<tr>
<td><strong>RHD Secondary Prophylaxis</strong></td>
<td>This project will implement and evaluate an intervention package aimed at improving health systems to increase delivery of Secondary Prophylaxis in NT health centres.</td>
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<tr>
<td><strong>RHD Genetics</strong></td>
<td>To understand why some people appear to be susceptible to RHD while others are not despite being exposed to GAS</td>
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<tr>
<td><strong>RHD in Pregnancy</strong></td>
<td>This project aims to provide an evidence base to improve clinical care and outcomes for women with RHD in pregnancy and their babies.</td>
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<tr>
<td><strong>ARF Immunology</strong></td>
<td>This project aims to find markers in the blood that can be used to rapidly and accurately diagnose acute rheumatic fever so that people can get treatment they need as soon as they can.</td>
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<tr>
<td><strong>RHD Echo screening</strong></td>
<td>To evaluate role of early detection of RHD via echo screening in RHD control. To evaluate the economics of echo screening &amp; development of evidence-based diagnostic &amp; treatment echo screening protocols.</td>
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<tr>
<td><strong>WHF Pacific and International RHD programme</strong></td>
<td>Direct programme support provided to 5 countries (Fiji, Tuvalu, Nauru, Solomon Islands and Kiribati) as well as several studies, evaluations and projects.</td>
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THE NEXT GENERATION of HEALTHY HEARTS ...

Acknowledgements & thankyou

- Jennifer Cottrell
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