Rheumatic Fever in the
Bay of Plenty and Lakes District Health Boards
A review of the evidence and recommendations for action

Summary Report

Dr Belinda Loring
Public Health Medicine Registrar
Toi Te Ora – Public Health

June 2008
Acknowledgements

Dr Neil de Wet
Dr Chris Hewison
Dr Phil Shoemack
Dr Jim Miller
Mrs Lynnette Borissenko
Dr John Malcolm
Dr Chris Moyes
Dr Jeremy Armishaw
Dr Johann Morreau
Dr Neil Poskitt
Ms Sandra Ball
Executive Summary

Overview

Rheumatic fever is a preventable cause of serious illness and death in the Bay of Plenty and Lakes District Health Boards, almost exclusively affecting Māori children. It has been virtually eradicated in most developed nations, but its decline has plateaued in New Zealand. Each year in New Zealand, rheumatic heart disease kills twice as many people as cervical cancer, many of them young adults. It can be prevented by appropriate antibiotic treatment of sore-throats. Estimation of the size of the rheumatic fever problem relies on notification of cases to the Medical Officer of Health, and previous studies have found the illness to be significantly under-notified.

This review, to obtain a more accurate understanding of the true number of rheumatic fever cases in the Lakes and Bay of Plenty District Health Boards, coincides with the release of new national guidelines for the diagnosis, management and prevention of acute rheumatic fever. From the results of this review, and these guidelines, it is possible to formulate clear recommendations for action in order to seriously reduce the incidence and impact of rheumatic fever in this region.

Summary of key findings

- Through this review, the number of cases of rheumatic fever known to be diagnosed in the Bay of Plenty and Lakes DHBs (1999-2007) rose from 75 to 147, meaning that the number of cases is at least double the number previously thought.

- Under-notification is a significant problem, with only half the cases being notified to the Medical Officer of Health.

- The annual incidence of acute rheumatic fever in children in Lakes DHB (22/100,000) is nearly double the New Zealand rate, and in Bay of Plenty DHB (34/100,000) it is nearly three times the New Zealand rate. These rates are higher than recently documented rates in many developing countries.

- Parts of the Eastern Bay of Plenty, particularly the towns of Opotiki, Kawerau and Murupara have among the world’s highest recently documented rates of acute rheumatic fever in children (88-258/100,000).

- This review is unlikely to have uncovered all cases, so these estimates are still likely to be under-estimates, particularly for Lakes DHB.

- Most of the cases of rheumatic fever (89%) in the Bay of Plenty and Lakes are Māori.
The relative risk of contracting rheumatic fever for Māori in the Bay of Plenty DHB is 21 times the risk for non-Māori. The risk for Māori in Lakes DHB is 12 times that for non-Māori. The true disparity is likely to be even higher, as this review will not have detected all cases (particularly for Lakes DHB).

Over 10% of ARF cases in the BOP/Lakes are recurrences, which could mostly have been prevented by optimum secondary prevention.

Strong evidence exists for the benefits of Rheumatic Fever Registers in reducing recurrent episodes of rheumatic fever by improving the tracking of patients requiring monthly antibiotics as secondary prevention.

Strong evidence exists for the effectiveness of school based throat swabbing programmes, in preventing rheumatic fever in children.

Clear national guidelines exist for the introduction of such school-based throat swabbing programmes, and a number of communities in the Bay of Plenty DHB meet the recommended incidence threshold to consider such programmes.

Strong evidence exists for the spread of Group A streptococcal throat infection within households.

Clear national guidelines exist for the testing and treatment of household contacts of patients recently diagnosed with rheumatic fever.

**Recommendations for further actions**

The burden of rheumatic fever in this region could be greatly reduced through a combination of simple actions, including awareness raising among communities and health professionals, improving existing secondary prevention efforts by establishing a register, and implementing proven primary prevention strategies such as school-based throat swabbing in communities at exceptionally high risk.

- A computerised rheumatic fever register should be implemented locally. Toi Te Ora has already undertaken substantial work towards developing pilot register, but this process has stalled awaiting further funding and IT support.

- School-based throat swabbing programmes are indicated in Kawerau, Opotiki and Murupara.
o Funding should be available to develop and deliver school-based programmes in these communities, in collaboration with the communities and local health professionals.

o To maximise effectiveness, this process should be viewed as an opportunity to develop capacity within these communities, and facilitate communities in developing a local approach appropriate to that community, rather than importing a pre-designed model.

- A community awareness campaign that “sore throats matter” should be delivered in conjunction with any school based programme, and in other high risk areas.

- Awareness-raising amongst general practitioners is also indicated, regarding the new New Zealand recommendations for antibiotic treatment of sore throats, prioritising general practitioners in high risk communities first.

- Testing and treatment of household contacts of new rheumatic fever cases should occur as described in the national guidelines, and as suggested in the draft Toi Te Ora protocol (Appendix 7).

- Ongoing annual analysis of rheumatic fever rates, at a DHB, council and community level should be undertaken by Toi Te Ora, using the same methods in this review, and this information should be reported annually to, at a minimum, the DHBs and communities concerned. This should occur until the disease is eradicated, or at least until in line with other developed nations.

- The Bay of Plenty and Lakes could benefit from sharing approaches and expertise on rheumatic fever with other District Health Boards who are currently active in the area, such as by hosting a New Zealand Rheumatic Fever Hui or similar forum.

- An audit of rheumatic fever hospital admissions should be performed for Lakes DHB, as without this, the analyses contained in this report are likely to disproportionately underestimate the true rate of rheumatic fever in Lakes DHB.
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<th>Description</th>
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<tbody>
<tr>
<td>ARF</td>
<td>Acute Rheumatic Fever</td>
</tr>
<tr>
<td>ATSI</td>
<td>Australian Aboriginal or Torres Strait Islander</td>
</tr>
<tr>
<td>BOP</td>
<td>Bay of Plenty District Health Board</td>
</tr>
<tr>
<td>CAU</td>
<td>Census Area Unit</td>
</tr>
<tr>
<td>CRHD</td>
<td>Chronic Rheumatic Heart Disease</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>DN</td>
<td>District Nursing</td>
</tr>
<tr>
<td>ESR</td>
<td>Environmental Science and Research</td>
</tr>
<tr>
<td>GAS</td>
<td>Group A Beta-haemolytic Streptococcus</td>
</tr>
<tr>
<td>GP</td>
<td>General Practice / Practitioner</td>
</tr>
<tr>
<td>IT</td>
<td>Information Technology</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MOH</td>
<td>Medical Officer of Health</td>
</tr>
<tr>
<td>NHI</td>
<td>National Health Index</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary Health Organisation</td>
</tr>
<tr>
<td>PHU</td>
<td>Public Health Unit</td>
</tr>
<tr>
<td>RFR</td>
<td>Rheumatic Fever Register</td>
</tr>
<tr>
<td>RR</td>
<td>Relative Risk</td>
</tr>
<tr>
<td>TLA</td>
<td>Territorial/Local Authority</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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1. Introduction

This is the summary report of a review undertaken by Toi Te Ora – Public Health (Toi Te Ora) on acute rheumatic fever (ARF) in the Bay of Plenty and Lakes District Health Boards, specifically focusing on:

- Retrospectively improving the completeness of ARF notifications, to obtain a more accurate understanding of disease rates in the region.
- A geographic analysis of disease incidence to identify high risk communities.
- A review of the evidence for primary prevention programmes.
- Improvement of local protocols for notification and contact tracing.

The overall aim of this review is to contribute to reducing the incidence of ARF in the Bay of Plenty/Lakes DHBs, by providing robust analysis of local data, national guidelines and national/international evidence in conjunction with clear recommendations, to inform efforts to tackle this disease in the region.

1.1 Specific project objectives

- To provide a more accurate estimation of the true incidence and distribution of ARF in the Bay of Plenty/Lakes region between 1999-2007, in light of the apparent level of under-reporting for this condition.
- To identify any geographic clusters within the region, to enable interventions to be targeted specifically to areas of high need which may benefit from the implementation of primary prevention school-based throat swabbing programmes.
- To make recommendations for the implementation of primary prevention interventions, such as school-based throat swabbing programmes, in communities that are found to have a high incidence of ARF.
- To develop an evidence-based protocol for ARF contact management in the Bay of Plenty/Lakes DHBs.

1.2 Rationale

ARF is preventable disease affecting mostly children and young people, with serious and often fatal consequences. ARF has been largely eliminated in most developed countries, but remains high in New Zealand amongst Māori and Pacific children. This results in an unacceptable and avoidable inequality. Treating Group A streptococcal throat infections
with antibiotics can prevent most cases of ARF. Recent evidence-based guidelines produced by the New Zealand Heart Foundation(1) found strong evidence in favour of school-based throat treatment programmes in preventing new cases of ARF (Grade A recommendation, Level II evidence).

1.3 Overview of ARF

Acute rheumatic fever (ARF) is a serious, preventable auto-immune disease mostly affecting children and adolescents. It is caused by an abnormal immune reaction to a Group A beta-haemolytic streptococcal (GAS) throat infection. Unfortunately, it is not possible to predict which patients with this type of throat infection will go on to develop ARF (1). There is however good evidence from randomised control trials that most cases of ARF can successfully be prevented by starting antibiotics within 9 days of the onset of a sore throat caused by GAS (2). Over 60% of those who have ARF will suffer long-term heart damage, or chronic rheumatic heart disease (CRHD)(2).

1.4 ARF in New Zealand

ARF has been virtually eliminated in most developed nations, however Māori and Pacific New Zealanders suffer among the world’s highest rates of ARF (40-100/100 000 children) (2). In contrast, the rate amongst New Zealand European children is very low, at 1/100,000 (3). Figure 1 contrasts recent published incidence rates in children from a number of different countries, including ethnic sub-populations in New Zealand and Australia. This graph should be treated as indicative only, as it compiles data from separate studies published after 1990, relating to slightly different years and age ranges. Overall in New Zealand in 2006 there were 103 notified cases of ARF, giving a crude incidence of 2.5 per 100,000 (4). Most of the ARF in New Zealand occurs in the northern, central and eastern regions of the North Island, corresponding with areas that have the largest Māori populations. In contrast to most other developed nations, the decline of ARF in New Zealand appears to have plateaued, with Figure 2 demonstrating relatively stable numbers of notifications each year since 1996.
Figure 1 - ARF incidence in children (rate per 100,000), from selected countries with rates published after 1990 [adapted from (2)]

Figure 2 - Number of annual ARF notifications in New Zealand 1996-2006
Chronic rheumatic heart disease (CRHD) is a significant cause of death in New Zealand, with an average of 145 deaths per year (5). To put this number in perspective, over twice as many New Zealanders die each year from CRHD than from cervical cancer. The age standardised mortality rate for CRHD for Māori is 6.0/100,000 and is over 7.5 times higher than the age-standardised mortality rate in non-Māori. Importantly, in contrast to ischaemic heart disease, CRHD is a major cause of death amongst younger adults. Māori with CRHD are more likely to die younger than non-Māori with CRHD (5).

Rheumatic fever is a disease for which there are huge and avoidable ethnic inequalities in New Zealand. There is no evidence of a genetic explanation for the higher rates of ARF amongst Māori and Pacific children (6). They are more likely explained by other determinants such as overcrowding, socio-economic deprivation, increased incidence of upper respiratory infections and differential access to and treatment within health services (6-9). Of particular concern is that even though Māori are over 7 times more likely than non-Māori to die from CRHD, they are only twice as likely as non-Māori to receive valvular surgery (5).

1.5 ARF in Bay of Plenty and Lakes

In 2007, Dr Neil de Wet (10) reviewed the current public health contribution to prevention and management of ARF in the Bay of Plenty and Lakes DHBs. He found that notification data in the region is incomplete, with an estimated 40-50% of ARF un-notified. He reported that national guidelines suggest that household contact tracing for ARF is the responsibility of public health units, however Toi Te Ora currently has no consistent approach to contact tracing for ARF, exacerbated by the low rates and timeliness of notification. He also noted that Toi Te Ora is not currently involved in any primary prevention programmes for ARF.

Based on his review, de Wet made the following recommendations to Toi Te Ora (10):

1. Develop an ARF register (initiated by de Wet but not yet operational - currently requiring additional IT support).

2. Strengthen notification procedures for ARF, to improve the percentage of ARF cases being notified.

3. Retrospectively improve the completeness of notification data using hospital and district nursing records.

4. Provide an analysis of clusters/high risk communities that may benefit from primary prevention.
5. Review and strengthen Toi Te Ora protocols for contact tracing.

Building on de Wet’s work and his recommendations above, this project will address recommendations 2, 3, 4 and 5.

1.6 Alignment of this project with Toi Te Ora and national priorities

1.6.1 Alignment with Toi Te Ora Service Plan (11)

- Primary strategic objectives for Toi Te Ora are to reduce health inequalities, and to strengthen public health action for Māori (11).

- In addition, Toi Te Ora commits to “make better use of research and evaluation in developing public health policy and practice”(11 p17). The New Zealand best practice guidelines recommending school-based prevention programmes for ARF have just been released, and such programmes have already been implemented with acclaimed results by Northland PHU. Toi Te Ora has an opportunity here to demonstrate rapid responsiveness in incorporating best practice guidelines.

- It is highly appropriate that Toi Te Ora take a leadership role in rheumatic fever prevention: “as the public health unit (PHU) for BOP and Lakes DHBs, Toi Te Ora is the lead local agency with responsibility for ensuring a reduction in the incidence and impact of infectious diseases”(11 p200)

- Toi Te Ora’s Communicable Disease Programme commits to “focus on those groups with the highest rates of communicable disease eg Māori” (11) and notes that rheumatic fever is almost exclusively a disease of Māori children.

1.6.2 Alignment with National Strategies & Legislation

- Reducing health inequalities is an overarching goal of the Ministry of Health and is reflected in the statutory responsibilities of DHBs (12).

- Reducing the incidence and impact of cardiovascular disease is one of the 13 priority objectives for the New Zealand Health Strategy 2000 (13).

- The Integrated Approach to Infectious Disease: Priorities for Action 2002-2006(14) sets out the framework for addressing the New Zealand Health Strategy objective “to reduce the incidence and impact of infectious diseases”.

  - Rheumatic fever is listed under infectious respiratory diseases as part of the six “highest priority” disease groups
This document contains a specific strategy to “promote, implement and evaluate primary prevention strategies for rheumatic fever, viral respiratory infections and community acquired pneumonia” (14 p20). It is clearly listed as the responsibility of DHBs and public health services to “implement best practice primary prevention programmes for rheumatic fever” (14 p23).
2. Methods

The methods for each component of this project are as follows:

2.1 Retrospectively improving notification data:

The EpiSurv database (the national database of notifiable conditions maintained by ESR) was searched to obtain a baseline list of all cases of ARF notified within the Bay of Plenty/Lakes DHBs between 1999-2007. The range of years was kept as broad as possible, as it was thought this list may go on to form the basis of a local rheumatic fever register, and ARF cases are usually given penicillin prophylaxis for at least 10 years after diagnosis (6). The year 1999 was chosen as the earliest limit as complete data was not available from the sources used prior to this year.

A list of potential ARF cases in the BOP/Lakes was then sought from the following sources:

- An audit of hospital discharge data for Whakatane and Tauranga hospitals, searching records between 1999-2007 for coding related to ARF (conducted by Dr Chris Hewison in 2007).
- BOP district nurse records of people in the BOP DHB requiring regular penicillin prophylaxis due to ARF.
- A register of patients on penicillin prophylaxis for ARF maintained by the Rotorua General Practice Group (RGPG), for patients in areas of Lakes DHB served by this group (mostly Rotorua and Murupara).
- A database from a Lakes DHB paediatrician, listing patients seen with ARF.
- Paediatricians’ (in Tauranga, Whakatane & Rotorua) individual knowledge of any additional cases not identified by above means

Cases obtained from the above sources were then compiled into separate spreadsheets for each DHB, and classified as either “notified” or “potential” ARF cases. The lists of “potential” ARF cases were then sent to paediatricians in the respective DHBs, to confirm whether these patients met the criteria for ARF. Any confirmation received from a paediatrician was treated as a notification, and the case was then entered into EpiSurv. Verification of the status of any patients not clarified through this process was sought by contacting the patient’s GP, and if necessary verifying details from the patient’s paper hospital chart.
For all of the confirmed cases, particular effort was made to ensure accurate information was available for ethnicity and location of residence at time of diagnosis. Even for previously notified ARF cases, if “ethnicity” or “address at time of diagnosis” were not recorded on the EpiSurv database, this information was sought initially by searching case’s NHI number on the DHB clinical information system, or if necessary, by telephoning the patient’s GP or paediatrician. Some of the ARF cases identified through this process were diagnosed earlier than 1999. These cases were still entered into the EpiSurv database, but were excluded from further analyses.

2.2 Geographical cluster analysis:

Using the updated spreadsheet of confirmed ARF cases diagnosed in the BOP/ Lakes DHBs, the home address at the time of diagnosis for each case was classified according to DHB, Territorial/Local Authority (TLA) and census area unit (CAU). For these analyses, recurrent episodes (a new episode of ARF in a patient who has previously had an episode of ARF) were counted in the same way as initial episodes. The data were then analysed, using Microsoft Excel to determine raw numbers of:

- All ARF cases, 1999-2007, by ethnicity and by DHB, TLA and CAU
- All ARF cases, 2003-2007, by ethnicity by DHB, TLA and CAU
- ARF cases in children aged 5-14 years (at time of diagnosis), 1999-2007, by ethnicity and by DHB, TLA and CAU
- ARF cases in children aged 5-14 years (at time of diagnosis), 2003-2007, by ethnicity and by DHB, TLA and CAU

Population denominator data for each TLA and CAU were obtained from the adjusted population estimates from Statistics New Zealand (these estimates are adjusted from the raw census figures to account regional estimates of under-reporting, non-return of census forms etc). For 1999-2007 analyses, the average of estimates from 1996, 2001 and 2006 censuses was used to account for fluctuating population numbers over the period. For 2003-7 analyses, estimates from the 2006 census only were used. These data were used to calculate:

- Annualised ARF incidence rates (1999-2007) for:
  - Total population, by ethnicity for each DHB, TLA and CAU
  - Children aged 5-14 years, by ethnicity, for each DHB, TLA and CAU

- Annualised ARF incidence rates (2003-2007) for:
2.3 Primary prevention:

A detailed literature review was conducted to search for evidence regarding the effectiveness for primary prevention programmes for ARF. A search was performed of the electronic databases MEDLINE, CINAHL, EMBASE, and the Cochrane Library using combinations of the keywords “rheumatic fever” “prevention” “primary” “programme” and “intervention”. The search was limited to a publication date after 1966, and the English language. To locate unpublished and grey literature, internet searches using Google and Google Scholar were conducted using the same search terms.

The geographical incidence rates calculated above were compared to thresholds recommended in the literature, for considering the implementation of school-based throat swabbing programmes. For communities with incidence rates above these thresholds, preliminary discussions were then sought with relevant stakeholders in these affected locations to share the results of this analysis, and explore options for primary prevention.

2.4 Contact tracing and notification processes

Discussions were sought with paediatricians separately in Whakatane, Rotorua/Taupo and Tauranga to:

- Discuss current New Zealand guidelines for the investigation and treatment of household contacts of ARF cases
- Discuss and develop local procedures for the management of household contacts of acute ARF cases, including clarifying the role of Toi Te Ora.
- Discuss the requirements and procedures for notifying ARF cases to the Medical Officer of Health
- If required, tailor the notification processes for each site, to improve the timely notification of any probable or confirmed ARF cases.
3. Results

3.1 Retrospective ARF notifications

A total of 190 ARF cases were confirmed through this review. A number of these cases (n=43) were either diagnosed outside of the BOP/Lakes DHBs or were diagnosed earlier than 1999, and these cases were excluded from the analyses. Out of the remaining 147, 122 were children aged 5-14 years. From this review, the number of notified cases of ARF diagnosed in the BOP and Lakes between 1999-2007 rose from 75 to 147 – an increase of 72 cases or almost 100%. This means that at best, only half of the ARF cases diagnosed in the area were officially notified. This suggests that the true rate of ARF in the BOP/Lakes region over the last 10 years has been at least double the “apparent” rate calculated from notifications to the Medical Officer of Health.

This is also likely to be a conservative estimate, as it is highly unlikely that this project managed to detect 100% of previously un-notified cases. Of note, 2 cases, which had been missed through the standard methodological approach for this review, were detected opportunistically - 1 case was identified through an unrelated article in a local newspaper, and 1 was identified through an opportunistic conversation with a junior hospital doctor. No hospital discharge audit was conducted for Lakes DHB, so this review is especially likely to underestimate the rates of ARF for people living in Lakes DHB, and in Bay of Plenty DHB communities who may access Rotorua or Taupo hospitals as their closest hospital (eg Murupara).

Overall, 12% of the ARF cases diagnosed in BOP/Lakes DHBs between 1999-2007 were recurrent episodes, compared with 1.4% of ARF cases notified in New Zealand in 2003 (1). As Table 1 shows, the ethnic profile of initial and recurrent episodes was similar, however there were marked geographic differences. Whilst BOP DHB had two-thirds of the initial attacks, Lakes DHB had two-thirds of the recurrent episodes. Overall, 20% of ARF cases diagnosed in Lakes DHB were recurrences. After Rotorua District Council, Whakatane District Council (in BOP DHB) had the second highest number of recurrent episodes, however all of these were from Murupara, a town which has close links with Lakes DHB and a Rotorua-based PHO. Assuming that the rate of recurrent episodes should be roughly similar between the two DHBs, there is no obvious explanation for the disproportionately high rate of diagnosis of ARF recurrence in Lakes DHB. Small numbers make definitive conclusions difficult. The higher percentage of cases being recurrent in Lakes DHB might indicate that secondary prevention not as successful in this DHB, or it could be an indicator that not all initial attacks have been identified. Before making any further comparisons between these two DHBs, an audit of ARF hospital discharges ought
to be done for Lakes DHB, (as it was for BOP) to enable ARF data to be compared from an equal range of sources.

Table 1 - Comparison of recurrent versus initial episodes on ARF, by ethnicity and location (for all cases diagnosed 1999-2007)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>No of cases</th>
<th>% TLA</th>
<th>No. of cases</th>
<th>% DHB</th>
<th>No. of cases</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Maori</td>
<td>113</td>
<td>86.9%</td>
<td>37</td>
<td>28.5%</td>
<td>88</td>
<td>67.7%</td>
</tr>
<tr>
<td>NZ European</td>
<td>9</td>
<td>6.9%</td>
<td>32</td>
<td>24.6%</td>
<td>42</td>
<td>32.3%</td>
</tr>
<tr>
<td>Pacific</td>
<td>6</td>
<td>4.6%</td>
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<td>15.4%</td>
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</tr>
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<td>Unknown</td>
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<td>1.5%</td>
<td>14</td>
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<td>8.5%</td>
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<td>10</td>
<td>7.7%</td>
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<td></td>
<td>6</td>
<td>4.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Totals</td>
<td>130</td>
<td>130</td>
<td>100%</td>
<td>130</td>
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<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>No of cases</th>
<th>% TLA</th>
<th>No. of cases</th>
<th>% DHB</th>
<th>No. of cases</th>
<th>%</th>
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<tbody>
<tr>
<td>Maori</td>
<td>15</td>
<td>88.0%</td>
<td>10</td>
<td>58.8%</td>
<td>6</td>
<td>35.3%</td>
</tr>
<tr>
<td>NZ European</td>
<td>1</td>
<td>6.0%</td>
<td>4</td>
<td>23.5%</td>
<td>11</td>
<td>64.7%</td>
</tr>
<tr>
<td>Pacific</td>
<td>1</td>
<td>6.0%</td>
<td>2</td>
<td>11.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>5.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Totals</td>
<td>17</td>
<td>17</td>
<td>100%</td>
<td>17</td>
<td>100%</td>
</tr>
</tbody>
</table>

3.2 Geographical analysis of ARF incidence

Table 2 shows the geographic breakdown of all ARF cases diagnosed in the BOP/Lakes between 1999-2007. In concurrence with other New Zealand data, the burden of ARF falls almost exclusively on Māori (89%) compared with non-Māori (11%).
Table 2 - Notifications of Acute Rheumatic Fever by TLA & DHB 1999-2007 (all ages)

<table>
<thead>
<tr>
<th>Area (TLA or DHB)</th>
<th>Total no. of cases</th>
<th>No. of Māori cases</th>
<th>No. of non-Māori cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opotiki</td>
<td>12</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Kawerau</td>
<td>11</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Whakatane</td>
<td>41</td>
<td>38</td>
<td>3</td>
</tr>
<tr>
<td>Rotorua</td>
<td>42</td>
<td>36</td>
<td>6</td>
</tr>
<tr>
<td>Tauranga</td>
<td>20</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>Taupo</td>
<td>7</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Western Bay</td>
<td>14</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>49</td>
<td>43</td>
<td>6</td>
</tr>
<tr>
<td>BOP DHB</td>
<td>98</td>
<td>87</td>
<td>11</td>
</tr>
</tbody>
</table>

As Table 3 and Table 4 show, the incidence rates of ARF in both the BOP and Lakes DHBs are higher than the New Zealand average. The rates are strikingly high in the Eastern Bay of Plenty area, in the Opotiki, Kawerau and Whakatane councils. In particular, the incidence of ARF in Opotiki District Council is almost 10 times the New Zealand rate. The ethnic disparity is more marked in the BOP DHB than in Lakes DHB, with BOP Māori experiencing over 20 times the incidence of ARF compared to non-Māori. This is influenced particularly by the high rates of ARF in Māori in the Eastern Bay of Plenty. This information is depicted graphically in Figures 3 and 4. Explanatory power for Māori is reasonably strong in these analyses, as both BOP and Lakes DHBs have high proportions of Māori in the population – 37% of children aged 5-14 years in BOP DHB are Māori and 45% in Lakes DHB (15). The Lakes DHB data are likely to underestimate the true ethnic disparity in ARF incidence more than the BOP DHB data, as a hospital audit has not been done in Lakes DHB to detect extra cases (as most ARF cases are Māori, any cases which this review failed to detect are most likely Māori, and the incidence rates for Māori will be appear lower without these cases included, and thus the observed gap between Māori and non-Māori will appear narrower than the true gap). Unfortunately, no analysis of national ARF incidence data by ethnicity is available for comparison.

As the majority of ARF cases (83%) occurred in children 5-14 years, the regional pattern of incidence rates for children is similar to the overall trends, although obviously the rates for children are much higher. To put these rates in perspective, an annual incidence of 165/100,000 for Māori children in Opotiki TLA means that 1.65 children per 1000 get ARF each year, and that over 10 years of childhood (between 5-14 years), 1 in 60 Māori
children in Opotiki District Council will develop ARF, compared to 1 in 10,000 for a non-Māori child in New Zealand.

Table 3 – Annualised incidence rates of Acute Rheumatic Fever by TLA &DHB 2003-7 (all ages)

<table>
<thead>
<tr>
<th>Area (TLA or DHB)</th>
<th>Incidence /100,000</th>
<th>Incidence Māori/ 100,000</th>
<th>Incidence non-Māori /100,000</th>
<th>RR for Māori compared with non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Zealand¹</td>
<td>2.5</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Opotiki</td>
<td>23.91</td>
<td>41.67</td>
<td>0</td>
<td>uncalculatable</td>
</tr>
<tr>
<td>Kawerau</td>
<td>16.78</td>
<td>27.84</td>
<td>0</td>
<td>uncalculatable</td>
</tr>
<tr>
<td>Whakatane</td>
<td>13.33</td>
<td>29.17</td>
<td>1.99</td>
<td>14.7</td>
</tr>
<tr>
<td>Rotorua</td>
<td>7.34</td>
<td>17.00</td>
<td>1.84</td>
<td>9.2</td>
</tr>
<tr>
<td>Tauranga</td>
<td>2.25</td>
<td>8.91</td>
<td>0.90</td>
<td>9.9</td>
</tr>
<tr>
<td>Taupo</td>
<td>1.80</td>
<td>6.35</td>
<td>0</td>
<td>uncalculatable</td>
</tr>
<tr>
<td>Western Bay</td>
<td>1.39</td>
<td>5.26</td>
<td>0.56</td>
<td>9.4</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>3.55</td>
<td>14.06</td>
<td>1.19</td>
<td>11.8</td>
</tr>
<tr>
<td>BOP DHB</td>
<td>5.18</td>
<td>19.38</td>
<td>0.93</td>
<td>20.8</td>
</tr>
</tbody>
</table>

¹ New Zealand rates are for 2006, from ESR Annual Report (4)
² Population denominators from Stats NZ June 2006 Population Estimates
### Table 4 – Age specific (5-14 years) incidence rates of Acute Rheumatic Fever by TLA & DHB 2003-7

<table>
<thead>
<tr>
<th>Area (TLA or DHB)</th>
<th>Incidence /100,000</th>
<th>Incidence Māori/100,000</th>
<th>Incidence non-Māori/100,000</th>
<th>RR for Māori compared with non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Zealand</td>
<td>13.8</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Opotiki</td>
<td>125.00</td>
<td>165.41</td>
<td>0</td>
<td>uncalculatable</td>
</tr>
<tr>
<td>Kawerau</td>
<td>88.24</td>
<td>112.15</td>
<td>uncalculatable</td>
<td></td>
</tr>
<tr>
<td>Whakatane</td>
<td>69.54</td>
<td>115.94</td>
<td>7.72</td>
<td>15.0</td>
</tr>
<tr>
<td>Rotorua</td>
<td>26.04</td>
<td>41.96</td>
<td>10.34</td>
<td>4.1</td>
</tr>
<tr>
<td>Tauranga</td>
<td>14.76</td>
<td>33.57</td>
<td>7.45</td>
<td>4.5</td>
</tr>
<tr>
<td>Taupo</td>
<td>12.02</td>
<td>28.71</td>
<td>uncalculatable</td>
<td></td>
</tr>
<tr>
<td>Western Bay</td>
<td>9.04</td>
<td>22.99</td>
<td>4.08</td>
<td>5.6</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>21.80</td>
<td>38.41</td>
<td>6.90</td>
<td>5.6</td>
</tr>
<tr>
<td>BOP DHB</td>
<td>33.87</td>
<td>78.23</td>
<td>6.33</td>
<td>12.4</td>
</tr>
</tbody>
</table>

1 New Zealand age-specific rates are for 1995-2000, from (3)

These data were analysed by Census Area Unit (CAU) to determine whether areas of high ARF incidence could be pin-pointed more specifically, to better direct prevention strategies. A CAU is an area roughly the same size a suburb, containing 3000-5000 people. Opotiki CAU for example, refers just to the township of Opotiki (population = 4000), whereas Opotiki TLA covers an area stretching from Ohope to Cape Runaway and includes a population of approximately 9000 (15). In contrast, Kawerau TLA and Kawerau CAU refer to virtually the same area. As shown in Table 5, this analysis highlights four CAUs with exceptionally high age–specific ARF incidence rates in children aged 5-14 years: Kawerau, Murupara, Opotiki and Whakatane West. Caution needs to be exercised in interpreting these data, as the numbers of cases are obviously smaller. Incidence rates were therefore not calculated for CAUs with less than 4 ARF cases in the 5 year period. Note that all of the cases in Table 4 are Māori.

An age specific annual incidence rate of 258/100,000, means that a child in Murupara has a 1 in 39 chance of developing ARF between the ages of 5-14 years. Based on an annual incidence of 139/100,000, a child in Opotiki CAU has a 1 in 70 chance of developing ARF between 5-14 years of age.
Table 5 - Age-specific (5-14 years) annual incidence rates of Acute Rheumatic Fever by selected Census Area Unit 2003-7

<table>
<thead>
<tr>
<th>Area</th>
<th>No. of cases 5-14 years</th>
<th>Incidence /100,000</th>
<th>Population aged 5-14 years ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Zealand</td>
<td>1</td>
<td>13.8</td>
<td></td>
</tr>
<tr>
<td>Kawerau</td>
<td>6</td>
<td>88.24</td>
<td>1360</td>
</tr>
<tr>
<td>Murupara</td>
<td>6</td>
<td>258.06</td>
<td>465</td>
</tr>
<tr>
<td>Opotiki</td>
<td>6</td>
<td>139.53</td>
<td>860</td>
</tr>
<tr>
<td>Whakatane west</td>
<td>4</td>
<td>126.98</td>
<td>630</td>
</tr>
</tbody>
</table>

¹ New Zealand age-specific rates are for 1995-2000, from (3)

² From Stats NZ June 2006 Population Estimates

Figure 3 and Figure 4 display graphically the annualised ARF incidence by TLA, DHB and CAU, compared with the New Zealand average. The red line in Figure 4 denotes the ARF incidence threshold to warrant school based throat swabbing programmes, according to the New Zealand Heart Foundation guidelines (1).

Figure 3 – Annualised ARF incidence/100,000 by TLA & DHB, for 2003-7(all ages)
Figure 5 and Figure 6 compare the ARF incidence rates for Māori compared with non-Māori in each of the TLAs and DHBs. Caution must be used when interpreting these graphs, as they are based on small numbers. Also, any under-detection of ARF cases is likely to downplay the true inequality between Māori and non-Māori, which may explain the lower incidence rates and narrower ethnic gap seen in Lakes DHB. The relationship between ARF incidence and NZDep is also not consistent. Whilst Murupara, Opotiki and Kaewrau are all NZDep 10 (the most deprived socio-economic decile), there are also many other NZDep 10 CAUs in the region, with equally high proportions of Māori children, without high rates of ARF. Also, rates of ARF for non-Māori living in NZDep 10 CAUs remain the same as the rates of ARF for non-Māori living in wealthier deciles. The rates of ARF for non-Māori living in NZDep 10 CAUs are lower than the incidence rates for Māori living in less deprived deciles.
Figure 5 - Comparison of Māori: non-Māori ARF incidence rates (2003-7) of ARF, by TLA and DHB

Figure 6 - Comparison of Māori: non-Māori age specific (5-14yrs) ARF incidence, 2003-7
3.3 Primary prevention of ARF

What does evidence recommend?

A recent meta-analysis found that there is good evidence of the effectiveness of school-based GAS sore throat interventions at reducing the incidence of new cases of ARF(1). This evidence was classified as grade A (rich body of high-quality randomised-control trial data), level II (evidence obtained from at least one properly designed randomised-control trial)(1). The same meta-analysis also found that both community-wide and combined community/school GAS sore throat interventions were effective at reducing the incidence of new cases of ARF (1). This international meta-analysis reviewed 11 studies (including from New Zealand), involving school or mixed school/community based primary prevention interventions for ARF. Studies which met the quality criteria and had an estimable relative risk (RR) were combined in the analysis depicted in Figure 7, showing an overall statistically significant reduction in ARF (RR=0.62) from school or mixed school/community based primary prevention interventions. Details of these individual studies, are summarised in Appendix 1.

---

**Figure 7 - Forest plot of studies preventing ARF, through mixed school/community projects (01) and school interventions (02) (From 1 p21)**

<table>
<thead>
<tr>
<th>Study</th>
<th>Treatment n/N</th>
<th>Control n/N</th>
<th>RR (95%CI Fixed)</th>
<th>Weight %</th>
<th>RR (95%CI Fixed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>01 Before after school and community</td>
<td>6 / 15600</td>
<td>29 / 31200</td>
<td>0.41[0.17,1.00]</td>
<td>18.7</td>
<td>0.41[0.17,1.00]</td>
</tr>
<tr>
<td>Subtotal(95%CI)</td>
<td>6 / 15600</td>
<td>29 / 31200</td>
<td>0.41[0.17,1.00]</td>
<td>18.7</td>
<td>0.41[0.17,1.00]</td>
</tr>
<tr>
<td>Test for heterogeneity chi-square=0.0 df=0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test for overall effect z=-1.97 p=0.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Treatment n/N</th>
<th>Control n/N</th>
<th>RR (95%CI Fixed)</th>
<th>Weight %</th>
<th>RR (95%CI Fixed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>02 Primary prevention in schools control vs intervention</td>
<td>36 / 353936</td>
<td>29 / 194960</td>
<td>0.66[0.42,1.12]</td>
<td>36.1</td>
<td>0.66[0.42,1.12]</td>
</tr>
<tr>
<td>Coulthard 1980</td>
<td>7 / 67792</td>
<td>17 / 63904</td>
<td>0.39[0.16,0.94]</td>
<td>16.9</td>
<td>0.39[0.16,0.94]</td>
</tr>
<tr>
<td>Lennon 2006</td>
<td>24 / 32254</td>
<td>29 / 31531</td>
<td>0.91[0.47,1.79]</td>
<td>20.3</td>
<td>0.91[0.47,1.79]</td>
</tr>
<tr>
<td>Subtotal(95%CI)</td>
<td>67 / 43986</td>
<td>75 / 290485</td>
<td>0.67[0.48,0.93]</td>
<td>81.3</td>
<td>0.67[0.48,0.93]</td>
</tr>
<tr>
<td>Test for heterogeneity chi-square=1.95 df=2 p=0.38</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test for overall effect z=-2.39 p=0.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Treatment n/N</th>
<th>Control n/N</th>
<th>RR (95%CI Fixed)</th>
<th>Weight %</th>
<th>RR (95%CI Fixed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total(95%CI)</td>
<td>73 / 460582</td>
<td>104 / 321685</td>
<td>0.62[0.45,0.85]</td>
<td>100.0</td>
<td>0.62[0.45,0.85]</td>
</tr>
<tr>
<td>Test for heterogeneity chi-square=2.98 df=3 p=0.39</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test for overall effect z= -3.02 p=0.003</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
What is currently being done in BOP/Lakes?

There are no current school or mixed school/community based projects interventions in the Bay of Plenty or Lakes aimed at reducing the incidence of ARF. There is no record of any past school or community based primary prevention projects in Lakes or Bay of Plenty.

What are other parts of NZ doing?

The Northland Medical Officer of Health and PHU implemented a school-based rheumatic fever primary prevention programme in Whangaroa in 2002. Prior to the intervention the age-specific rates of disease in children 5-14 years were the highest recorded in New Zealand at 424/100,000 and all cases were Māori (16). The last case from this area occurred 8 days after the programme started in 2002. The programme was developed in collaboration with the local Māori health trust, and involved a health worker visiting the local school three times per week, and swabbing the throats of any children who reported having a sore throat. Any child whose swab tested positive for GAS was given a 10 day oral course of antibiotics (with the script written by the local MOH, and antibiotics delivered by the health worker who also checked on compliance). The programme was accompanied with a community wide “sore throats matter” awareness campaign.

Factors that were associated with the successful Whangaroa programme included (16):

1. Preceding community concern
2. Concern by local health care workers about the level of disease in the community
3. Support of the programme by the community paediatrician
4. Well-defined area with single iwi provider and primary health provider
5. The schools’ enrolled population consisted almost exclusively of children from the high incidence area
6. Partnership, participation, protection and “passion” – the iwi provider and primary health provider were both committed to the programme; the iwi provider acted as the local “champion” for the programme; there was joint decision making shared between the iwi provider; the primary health provider and the regional public health provider; the community and schools were very supportive; and local people were employed to do the throat swabbing in the schools
7. Awareness of the scale of the disease and willingness by the District Health Board and Ministry of Health to tackle a serious childhood disease with major inequalities

Since this successful Whangaroa programme, Northland PHU have commenced a similar programme in the larger community of Kaikohe. With the imminent release of the New Zealand Heart Foundation’s guidelines recommending school based programmes in high incidence areas, it is likely that more school based programmes will be considered in other parts of New Zealand soon.

**What should be done in the BOP/Lakes?**

In comprehensive 2008 guidelines, the New Zealand Heart Foundation, in conjunction with a writing group of national and international experts on ARF, recommended that Public Health Units in partnership with community paediatricians apply the following approach (1):

- Carry out an annual analysis of ARF notifications, assessing separately the notification rates at a community level where there are high numbers of Māori and Pacific. For consistency, analyse age-specific rates for children 5-14 years.

- If annualised age-specific rate of ARF in children 5-14yrs over last 5 years \( \geq 20 \text{ per } 100000 \), consider heightened public health action where such as:
  - Early detection and treatment of GAS pharyngitis
  - Advocacy/interventions regarding socioeconomic determinants of ARF (eg housing)

- If annualised age-specific rate of ARF in children 5-14yrs over last 5 years \( \geq 50 \text{ per } 100000 \), assess feasibility of a school-based programme where (see Appendix 2 for criteria to assess feasibility):
  - This requires community partnership approach (support from local paediatricians, iwi, Pacific providers, schools, primary care providers)
  - If widespread support, seek funding (from DHB or Ministry of Health)
At least three of the high risk communities in the BOP DHB, Murupara, Kawerau and Opotiki appear to be suitable candidates for a school-based throat swabbing programmes. They are all well defined, small communities, with schools mainly serving children from the specific communities themselves. Appendix 4 lists the schools in each of these three towns, including the numbers on the school roll, socioeconomic decile and percentage of students who are Māori. Secondary schools are included on this list, although communities may prefer to concentrate efforts on primary and intermediate schools (children aged 5-13).

3.4 Contact tracing for ARF

What does evidence recommend?

GAS pharyngitis is droplet spread, and the rate of GAS pharyngitis cross-infection within a household is between 19-50% (1). The attack rate of rheumatic fever, in those with untreated GAS is between 0.3-3% (17). Testing and treatment of close contacts for confirmed ARF cases has been proposed as a means to reduce the risk of ARF occurring in these people who have a high chance of having contracted GAS from the index case.

The New Zealand Heart Foundation's guidelines recommend:

- Trialling notifications of GAS pharyngitis to MOH in areas where the risk of ARF is particularly high, to test the effectiveness of this intervention (1).

- If within 1 month of onset of index case’s symptoms, all symptomatic and asymptomatic household contacts aged 3 years and over, should have a throat swab and be offered antibiotics if GAS positive (18).

What is currently being done in BOP/Lakes?

Toi Te Ora does not currently conduct household contact tracing for ARF. Paediatricians in Whakatane and Tauranga report that testing and treating household contacts is not something that they routinely do for newly diagnosed ARF cases. There is some evidence of multiple cases of ARF occurring within the same household/family in the region over last the 10 years, but no clear indication from onset dates that contact tracing would have prevented these cases.
What are other parts of New Zealand doing?

Currently, only Northland PHU has a clear protocol (Appendix 5) on the management of household contacts for ARF cases. This protocol is based on the New Zealand Heart Foundation Guidelines (18), and involves Public Health Nurses conducting throat swabs of all household contacts (over 3 years of age) of notified ARF cases, (if notified within 1 month of onset). Any throat swabs positive for GAS are treated with antibiotics prescribed by the MOH. This protocol applies to the entire Northland DHB, and not just communities where school-based throat programmes are implemented.

What should be done in BOP/Lakes?

The major factor limiting the implementation of ARF household contact tracing in the BOP/Lakes is the delay in notifying the case to the Medical Officer of Health. As contact tracing is currently not being done, it is difficult to know the most appropriate process. Also, it is slightly more difficult to engender support for contact tracing when it is uncertain if many or any of our region’s ARF cases in the last 10 years would have been prevented by active contact management. None of the ARF cases in the last 2 years at least have been notified to Toi Te Ora within 1 month of onset. As such, the first priority must be on improving the notification process for ARF. It may also be worthwhile for Toi Te Ora to develop and internal protocol, similar to Northland PHU’s, involving household contact management for all cases notified to the MOH within 1 month of onset, although unless notification processes improve, action on this protocol will not be frequently be required.

In order to improve the completeness and timeliness of ARF notifications, consultation with paediatricians in the BOP/Lakes was undertaken to determine how the notification process could be made easier and more appropriate. It was found that paediatricians in Tauranga and Whakatane had slightly different preferences for the method of communication best suited to their site, and as such it is likely that Toi Te Ora may need to tailor the notification process differently for each site to achieve optimum notification of ARF cases.

For the Tauranga paediatricians there was no one notification method preferred by all – some were happy to electronically complete the full EpiSurv form themselves, and email it to the Toi Te Ora Communicable Disease Co-ordinator. Others preferred to send a quick email with the patient’s name and NHI, and leave Toi Te Ora staff to obtain the full details required from the house surgeon or patient. Not all paediatricians were aware of the requirement to notify ARF.

In Whakatane, paediatricians themselves wished to be responsible for notifying ARF to Toi Te Ora. Printed versions of the current EpiSurv ARF notification form are available on the
paediatric ward, and will be filled in by the paediatrician responsible as soon as practicable after the child is admitted to hospital. This form will be posted directly to the Communicable Disease Co-ordinator at Toi Te Ora. Upon discharge, Whakatane have developed a checklist form for the discharge of ARF patients (Appendix 6) to facilitate handover to district nurse follow-up. A step asking whether the case has been notified to Toi Te Ora has been added to this form, to serve as a safety measure to catch any ARF cases that might not have been notified earlier in their admission.

The methods of communication used in this review were not as successful in engaging with Lakes paediatricians, so further effort needs to be undertaken to clarify the best way to improve ARF notifications for Lakes DHB.

A common issue raised in Tauranga and Whakatane, was that the notification of ARF cases could be compromised by the unfamiliarity of new and locum staff with ARF and the requirement to notify. Possible solutions to this could include:

- providing information on ARF in the orientation packs for all locum paediatric and medical staff
- placing reminder notices at the staff station on the paediatric wards
- encouraging charge nurse on paediatric ward to prompt doctors and remind junior/new medical staff
4. Discussion

As mentioned above, this project is still unlikely to have captured all ARF cases occurring in the BOP/Lakes in the last 10 years. Further cases may have been missed through such factors as hospital mis-coding, cases being admitted to hospital outside of BOP/Lakes (such as Waikato or Starship), cases not being admitted to hospital, cases relocating to another region after diagnosis. In addition, an audit of hospital discharge codes was not performed for Lakes DHB, so a higher number of un-identified ARF cases may exist in this area. This report found that the rates of ARF in Lakes DHB are approximately two-thirds the rates in BOP. Given that Lakes DHB also has a high proportion of Māori living in deprived situations, more detailed investigation of the ARF incidence in Lakes would be warranted to determine if the lower incidence rates found in this report are in fact a true representation.

Under-notification of ARF is a previously documented problems in New Zealand (18) with estimates from other areas ranging from 26-48%. The degree of under-notification found in this project (almost 50%) is higher than previously documented. There are a number of factors which contribute to the notification difficulties with ARF:

- ARF is a complicated diagnosis made according to a number of clinical criteria, rather than a simple positive or negative laboratory diagnosis

- Multiple health professionals are involved in the care of ARF cases, sometimes involving a number of different medical specialities and more than one hospital.

- ARF often involves a prolonged treatment course, with cases sometimes in hospital for several months.

- Staff trained overseas, especially in low incidence countries, may be unfamiliar with ARF and unaware of local notification requirements

- ARF remains an infrequently diagnosed condition for most professionals, meaning many staff may be unfamiliar with the notification requirements.

Calculations of incidence rates for ARF need to be interpreted with caution, as they are based on small numbers of cases, and small fluctuations in numbers can have a major effect on incidence rates. The calculations used in this report are based on those recommended in national guidelines, to ensure that the results of this report can be easily compared with other New Zealand data.
Aside from helping to reduce an avoidable cause of morbidity and mortality in children, and a source of extreme inequality for Māori, school based throat swabbing programmes appear favourable in cost benefit terms. Based on Northland figures, the total cost of running a school-based throat swabbing programme, is approximately $70 per school child per year. Applying this figure to local high risk communities, assuming outcomes similar to the Whangaroa programme, gives the following cost estimates:

**Murupara:**
- 465 children, with 1.2 cases per year
- $32,550 per year to prevent 1.2 cases
- $27,125 to prevent 1 case of ARF

**Opotiki:**
- 860 children, with 1.2 cases per year
- $60,200 per year, to prevent 1.2 cases
- $50,167 to prevent 1 case of ARF

**Kawerau:**
- 1360 children, with 1.2 cases per year
- $95,200 per year to prevent 1.2 cases
- $79,333 to prevent 1 case of ARF

In comparison, the costs of ARF are great – based on 1997 costs, de Wet estimated the BOP/Lakes DHBs spend $675,000 per year on rheumatic fever related costs. Based on an average of 10 new cases per year, gives a rough estimate of $67,500 in direct costs to the DHBs per ARF case. Approximately 70% of this cost is spent on CHRD, and 30% on ARF, so the maximum benefit of preventing new cases of ARF will not be seen immediately. This basic assessment however only includes the direct health care costs, and does not take into account the economic and social impact of lifelong morbidity and early death. Out of all cases (all ages) of ARF diagnosed in the BOP DHB over the last 10 years, 30% of them were children aged 5-14 years from the three high risk communities of Kawerau, Murupara and Opotiki suggesting that targeted primary prevention programmes in these three communities could prevent up to 30% of the ARF cases in BOP DHB.
5. Summary of findings

- ARF is a preventable disease with serious and often fatal long-term consequences. It is caused by a common throat infection, is virtually 100% preventable if treated with antibiotics, yet those who contract ARF have a 60% chance of long term heart damage.

- It has been virtually eradicated in most of the developed world.

- Whilst ARF is a notifiable disease, at least 50% of ARF in the BOP and Lakes DHBs in the last decade has not been notified. This has contributed to a serious under-estimation of the incidence and burden of ARF locally and nationally.

- The rates of ARF in certain communities in the Eastern Bay of Plenty are among the highest in the world (up to 258/100,000 children).

- The burden of ARF in BOP and Lakes overwhelmingly and almost exclusively affects Māori, and this inequality in incidence is more marked in the Eastern Bay of Plenty.

- In the BOP/Lakes DHBs, 12% of ARF cases are recurrent episodes, compared with 1.4% nationally. This disparity could reflect poorer notification of recurrent episodes generally in New Zealand, but it does mean that 12% of ARF cases in BOP/Lakes could be prevented by improved secondary prevention – a situation likely to be greatly assisted by a rheumatic fever register.

- Lakes DHB appears to have a disproportionately high number of recurrent episodes of ARF, suggesting either less successful secondary prevention or incomplete data on the true number of initial cases. This needs to be investigated urgently with an audit of ARF hospital admissions. If it is true that 20% of ARF cases diagnosed in Lakes DHB are recurrences, this gives further urgency to the implementation of a computerised register to improve delivery of secondary prevention.

- The entire BOP and Lakes DHBs have ARF incidence rates for the last 5 years above the threshold of 20/100,000 children recommended (in the NZ Heart Foundation Guidelines) for heightened public health action.

- Murupara, Kawerau, Opotiki and parts of Whakatane all have age-specific incidence rates in children 5–14 years (annualised, over the last 5 years, as recommended in the NZ Heart Foundation Guidelines) well above the threshold recommended for considering school-based throat swabbing programmes.
• Murupara, Kawerau and Opotiki meet a number of the criteria (16) recommended for communities to be good candidates for successful school-based throat swabbing programmes.

• The cost of preventing cases of ARF through school based programmes is less than the current direct costs to the DHBs in treating rheumatic fever.

• The testing and treatment of household contacts of new ARF cases, recommended by New Zealand guidelines (18), is not currently being done in BOP/Lakes DHBs.
6. Recommendations

Based on the findings of this report, it is recommended that ARF is treated as a priority area for Lakes and BOP DHBs, and that the following multi-pronged approach is taken:

1. Toi Te Ora should monitor, analyse and report on local epidemiology of ARF on an annual basis, to track the effectiveness of disease eradication efforts:
   a. in particular providing age-specific incidence rates in 5-14 year olds, by DHB, TLA and CAU

2. An audit of ARF hospital admissions should be performed for Lakes DHB, to determine whether the lower ARF incidence for Lakes DHB observed in this review is in fact true.

3. The rheumatic fever register must be prioritised urgently, and additional resources should be allocated to overcome IT delays – apart from the clear health and economic benefits to the DHBs outlined by de Wet (10), there is a real risk of damage to relationships with other professionals and stakeholders by Toi Te Ora not being able to deliver the register. Delivering the much anticipated register will boost the credibility and commitment of Toi Te Ora and facilitate our future efforts to collaborate regionally on ARF.

4. Toi Te Ora should develop a protocol for the public health response to new ARF cases, including the management of household contacts, similar to that used by Northland PHU. A suggested draft for this protocol is included in Appendix 6

5. Ongoing work needs to be undertaken to ensure medical staff at all hospitals in the BOP/Lakes DHBs are aware of the requirement and procedures to notify ARF. Specific actions still to be undertaken include placing reminder notices on paediatric wards and in medical staff orientation packs, and clarifying with Lakes paediatricians their preferred method of notifying ARF cases to Toi Te Ora, and any specific barriers to notification in Lakes which can be overcome.

6. Based on the current epidemiology, evidence, and cost-benefits, school-based throat swabbing programmes should be offered in the towns of Opotiki, Murupara and Kawerau. Toi Te Ora should take a leadership role in instigating this process, which would involve:
   a. Initial consultation and scoping with communities and key stakeholders
b. Securing funding from the DHB

c. Identifying and working with local partners to establish and deliver the programmes (including ordering laboratory tests and prescribing antibiotics through the MOH if preferred). The format used in Northland is suggested as an initial starting point for communities to adapt as appropriate to their specific needs.

d. Providing expertise and support to deliver concurrent community awareness-raising programmes (such as Northland’s “Sore Throats Matter” campaign)

e. Evaluating the process and impact of the programmes, to inform subsequent prevention efforts in this region and elsewhere.

7. The Bay of Plenty and Lakes DHBs could benefit from sharing approaches and expertise on rheumatic fever with other District Health Boards who are currently active in this field, such as by hosting a New Zealand Rheumatic Fever Hui or similar forum.
### Appendix 1 – Summary of studies relating to school based primary prevention programmes

<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chun, LT et al (1984)</td>
<td>Children from 156 public schools in Hawaii 1976-1980.</td>
<td>Observational study. 93 schools already had rheumatic fever clinics running, where children with sore throats reported to school health room, health aides took swabs, and any GAS positive were referred to normal health care provider for treatment and excluded from school until completed. This study observed numbers of ARF cases occurring in children from these schools with the number of cases from schools which did not have programmes.</td>
<td>Children in schools with clinics were less likely to develop ARF (RR 0.68, 95% CI = 0.42-1.12)</td>
</tr>
<tr>
<td>Coulehan, JL, et al (1982)</td>
<td>27,834-38,571 school children in Navajo reservation, Utah, 1975-79</td>
<td>Observational study. Reviewed all new ARF admissions, and determined whether child came from an intervention or non-intervention school. Intervention schools had rheumatic fever programmes which swabbed children with sore throats, but also screened entire school populations with throat cultures 1-9 times per year. All positive GAS swabs received antibiotics.</td>
<td>Children in schools with clinics were less likely to develop ARF (RR 0.39, 95% CI = 0.16-0.94)</td>
</tr>
<tr>
<td>Lennon, D. et al (2006)</td>
<td>24,000 children in decile 1 schools in South Auckland, 1998-2001.</td>
<td>Randomised-control trial. Half the schools were randomly allocated as controls, and half to have a GAS pharyngitis clinic in the school, swabbing and treating GAS pharyngitis.</td>
<td>29% reduction in ARF in schools with clinics, however not statistically significant. Large study but under-powered.</td>
</tr>
<tr>
<td>Phibbs, B (1975)</td>
<td>School children in 21 counties of Wyoming state, 1954-1969</td>
<td>Before and after intervention study. Teachers asked students each morning if they had cold or sore throat, and swabbed if they did. Also, each child had their throat inspected weekly, and swabbed if inflamed. Children with GAS positive swabs were sent home with a note advising treatment, and excluded from school until treated or with a negative swab.</td>
<td>There was a reduction in cases of ARF after the intervention, compared with before (RR 0.41, 95% CI = 0.17-1.00)</td>
</tr>
</tbody>
</table>
### Appendix 2 – Feasibility Assessment for school-based sore throat programmes for ARF prevention (1 p37)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Is the epidemiology of the disease well described:</td>
</tr>
<tr>
<td></td>
<td>• What is the annualised age-specific rate in children aged 5-14 years over the last 5 years?</td>
</tr>
<tr>
<td></td>
<td>• Are the numbers increasing, decreasing or stable?</td>
</tr>
<tr>
<td></td>
<td>• Are there ethnic disparities?</td>
</tr>
<tr>
<td></td>
<td>• How do the rates compare with national rates?</td>
</tr>
<tr>
<td></td>
<td>• Are there “hotspots” based on attendance at certain schools?</td>
</tr>
<tr>
<td></td>
<td>• Is there a high level of population mobility?</td>
</tr>
<tr>
<td>2.</td>
<td>Is there community (including schools) knowledge about rheumatic fever?</td>
</tr>
<tr>
<td>3.</td>
<td>Are the local schools supportive?</td>
</tr>
<tr>
<td>4.</td>
<td>Is there an understanding by local healthcare workers about the level of disease in the community and its preventability?</td>
</tr>
<tr>
<td>5.</td>
<td>Is the partnership between paediatricians and public health (if relevant to the area) ready to tackle these issues?</td>
</tr>
<tr>
<td>6.</td>
<td>Is the area well-defined? Do schools mainly take children from the high incidence area?</td>
</tr>
<tr>
<td>7.</td>
<td>Is there a community agency that can act as the local “champion”?</td>
</tr>
<tr>
<td>8.</td>
<td>Can the local health providers, iwi providers and regional public health provider work together in partnership with the community on this issue?</td>
</tr>
<tr>
<td>9.</td>
<td>Are the District Health Board and the Ministry of Health aware of the level of disease in the area and know about:</td>
</tr>
<tr>
<td></td>
<td>• The evidence supporting a school-based initiative from the meta-analysis of community intervention trials (including the New Zealand trial)?</td>
</tr>
<tr>
<td></td>
<td>• The effectiveness of the Northland rheumatic fever prevention programme which has eradicated rheumatic fever?</td>
</tr>
</tbody>
</table>
Appendix 3 – Algorithm for guiding Public Health Units in selection of appropriate strategies for primary prevention of acute rheumatic fever in small town and rural settings in New Zealand (1)

Are there well-defined communities within your region containing populations at high-risk for ARF i.e. Pacific people or Māori?

No

No further action is required as your ARF rates are very likely to be

<20 per 100,000

≥20 per 100,000

≥50 per 100,000

Yes

What are the annualised rates of ARF in children 5-14 yrs over the last 5 years in

Early detection and appropriate treatment of GAS pharyngitis strategies

Advocacy for strategies that address socio-economic determinants of health such as housing

Assess the feasibility of implementing a primary prevention school-based programme using a “community partnership” approach
### Appendix 4 – List of schools in candidate communities for school-based throat swabbing programmes (19)

#### Schools in Opotiki CAU

<table>
<thead>
<tr>
<th>School Name</th>
<th>Type</th>
<th>Decile</th>
<th>School roll</th>
<th>% Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ashbrook</td>
<td>Full Primary (Yr1-8)</td>
<td>1</td>
<td>228</td>
<td>95</td>
</tr>
<tr>
<td>St Joseph’s Catholic School</td>
<td>Full Primary (Yr1-8)</td>
<td>2</td>
<td>195</td>
<td>55</td>
</tr>
<tr>
<td>Opotiki School</td>
<td>Full Primary (Yr1-8)</td>
<td>1</td>
<td>277</td>
<td>97</td>
</tr>
<tr>
<td>Woodlands School</td>
<td>Full Primary (Yr1-8)</td>
<td>3</td>
<td>167</td>
<td>40</td>
</tr>
<tr>
<td>Opotiki College</td>
<td>Secondary (Yr 9-15)</td>
<td>1</td>
<td>554</td>
<td>76</td>
</tr>
</tbody>
</table>

#### Schools in Kawerau CAU

<table>
<thead>
<tr>
<th>School Name</th>
<th>Type</th>
<th>Decile</th>
<th>School roll</th>
<th>% Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kawerau Central School</td>
<td>Primary (Yr1-6)</td>
<td>1</td>
<td>91</td>
<td>90</td>
</tr>
<tr>
<td>Kawerau College</td>
<td>Secondary (Yr 9-15)</td>
<td>1</td>
<td>417</td>
<td>81</td>
</tr>
<tr>
<td>Kawerau Intermediate</td>
<td>Intermediate (Yr 7-8)</td>
<td>1</td>
<td>136</td>
<td>91</td>
</tr>
<tr>
<td>Kawerau North School</td>
<td>Primary (Yr1-6)</td>
<td>1</td>
<td>159</td>
<td>86</td>
</tr>
<tr>
<td>Kawerau South School</td>
<td>Primary (Yr1-6)</td>
<td>1</td>
<td>230</td>
<td>74</td>
</tr>
<tr>
<td>Putauaki School</td>
<td>Full Primary (Yr1-8)</td>
<td>2</td>
<td>385</td>
<td>77</td>
</tr>
</tbody>
</table>

#### Schools in Murupara CAU

<table>
<thead>
<tr>
<th>School Name</th>
<th>Type</th>
<th>Decile</th>
<th>School roll</th>
<th>% Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>Murupara School</td>
<td>Full Primary (Yr1-8)</td>
<td>1</td>
<td>249</td>
<td>97</td>
</tr>
<tr>
<td>Te Kura Kaupapa Motuhake o Tawhiua</td>
<td>Composite (Yr 1-15)</td>
<td>1</td>
<td>136</td>
<td>100</td>
</tr>
<tr>
<td>Rangitahi College</td>
<td>Secondary (Yr 7-15)</td>
<td>1</td>
<td>91</td>
<td>92</td>
</tr>
</tbody>
</table>
**Appendix 5 Northland PHU protocol for public health management of cases of ARF**

### NOTIFICATION OF CASE OF ACUTE RHEUMATIC FEVER

#### Public Health Follow-up

(follow-up should begin within 5 days of notification unless otherwise instructed by the Medical Officer of Health)

---

### CASE MANAGEMENT

**PUBLIC HEALTH**

1. Patient details entered onto Northland Rheumatic Fever Register. See attached Register Flowchart on page 2.

2. Ensure there are arrangements for cases to receive long-term penicillin prophylaxis as recommended by the paediatrician or physician:
   - the nurse for the area should do a ward and family visit if possible before patient is discharged
   - this visit is a time for the nurse to introduce him or herself, to discuss importance of penicillin chemoprophylaxis, handout resources, discuss dental visits, specialist visits and arrangements for penicillin injections
   - it is also important for the nurse to ask the patient (or caregiver) for their consent to let their local Iwi Provider know about the illness

---

### CONTACT MANAGEMENT

The rationale is to (1) reduce the risk of ARF in close contacts with GAS pharyngitis, and (2) reduce the environmental level of GAS before the index case returns home

1. All household contacts aged 3 years and older should have a throat swab (if the contact was no longer than 1 month before the onset of ARF in the index case).

   Patients who are unwell should be swabbed and advised to see their family doctor.

   The throat swab can either be carried out by the public health nurse or the contact can be referred to a medical laboratory.

   The PHN needs to complete a lab request form (either Northland Pathology Laboratory or a hospital laboratory) for each contact, sign it on behalf of the Medical Officer of Health and ask for a copy to be sent to the GP. Please write “close contact of XY” (initials of patient with RF) in Relevant Clinical Details box on lab request form.

2. All patients with growths of GAS should be offered antibiotic treatment. The Medical Officer of Health can write the prescriptions.

3. Benzathine penicillin LA is the drug of choice (see page 4):
   - Benzathine penicillin LA is appropriate as one dose therapy – children under 20kg 450mg (0.6 mega units) IM, for larger children and adults 900mg (1.2 mega units) IM
   - An alternative is oral treatment of compliance likely to be good: Penicillin V Children: 20mg/kg/day in 2-3 divided doses for 10 days. Maximum 500mg 3 times daily
     - Adults: 500mg twice daily for 10 days
   - Orally administrated erythromycin (EES) is indicated for patients allergic to penicillin. Erythromycin 40mg/kg per day in two to four divided doses for 10 days is recommended for children; the maximal dose is 1000mg/day. The adult dose is 400mg twice daily.
   - Education about group A streptococcal infections and the importance of early detection and treatment (this applies both to case and the family members)
Appendix 6 – Whakatane Hospital ARF discharge planning form

Rheumatic fever Whakatane Hospital

Paediatric Ward to District Nursing Service referral date / /200

<table>
<thead>
<tr>
<th>Circle, fill in or attach information</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Seen by DNS on ward</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Sticker Patient names</td>
<td>dob</td>
<td>NHI</td>
</tr>
<tr>
<td>Addresses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other contacts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dogs other issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paediatrician following up</td>
<td>Moyes</td>
<td>Ramadas</td>
</tr>
<tr>
<td>General practitioner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac involvement</td>
<td>Nil</td>
<td></td>
</tr>
<tr>
<td>Mitral stenosis/incompetence</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Aortic stenosis/incompetence</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Left, Right ventricular function</td>
<td>Normal</td>
<td>Abnormal</td>
</tr>
<tr>
<td>Arthritis at presentation</td>
<td>Present</td>
<td>Absent</td>
</tr>
<tr>
<td>Chorea, E marginatum, Nodules</td>
<td>Present</td>
<td>Absent</td>
</tr>
<tr>
<td>Prophylaxis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benzathine Penicillin &gt;20KG</td>
<td>1 Mega</td>
<td>900mg</td>
</tr>
<tr>
<td>&lt; 20 Kg 0.9Mega</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Next due</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration planned till age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EMLA lignocaine with prilocaine</td>
<td>Approval No.</td>
<td></td>
</tr>
<tr>
<td>School name</td>
<td>Attend From</td>
<td></td>
</tr>
</tbody>
</table>
Sport

Active families Sport BOP involved

Dietician involved name

Notifications made on EpiSurv form to ESR Porirua MOH BOPDHB register

Dental referral made to

Dental prophylaxis card given Yes

Discharge letter attached Yes

I parent have been given And explained

1/Information on rheumatic fever Including

2/How streptococcal throats cause Rh fever

3/Signs and symptoms Arthritis Shortness Of breath fatigue

4/How to prevent another attack with penicillin

5/How long treatment will be needed,

I have offered the person receiving This information opportunity

To answer questions and have Answered Them appropriately

And to the best of my ability signed
Appendix 7 – Recommended Toi Te Ora ARF case contact management protocol (DRAFT)

NOTIFICATION OF CASE OF ACUTE RHEUMATIC FEVER

Public Health Follow-up
(follow-up should begin within 5 days of notification unless otherwise instructed by the Medical Officer of Health)

CONTACT MANAGEMENT
The rationale is to: (1) reduce the risk of ARF in close contacts with GAS pharyngitis, and (2) reduce the environmental level of GAS before the index case returns home.

If within 1 month of onset of ARF in the index case:

1. All household contacts aged 3 years and older should have a throat swab:
   - The throat swab can either be carried out by the GP or the contact can be referred to a medical laboratory with a request form signed by the Medical Officer of Health.
   - Contacts who are unwell should be swabbed and advised to see their family doctor.
   - On the lab form, request a copy of swab results be sent to the GP. Please write “close contact of XY” (initials of patient with RF) in Relevant Clinical Details box on lab request form.

2. All patients with swabs positive for GAS should be offered antibiotic treatment. The Medical Officer of Health can write the prescriptions.

3. Benzathine penicillin LA is the drug of choice:
   - Benzathine penicillin LA is appropriate as one dose therapy – children under 20kg 450mg (0.6 mega units) IM, for larger children and adults 900mg (1.2 mega units) IM
   - An alternative is oral treatment of compliance likely to be good: Penicillin V Children: 20mg/kg/day in 2-3 divided doses for 10 days. Maximum 500mg 3 times daily
     * Adults: 500mg twice daily for 10 days
   - Orally administrated erythromycin (EES) is indicated for patients allergic to penicillin. Erythromycin 40mg/kg per day in two to four divided doses for 10 days is recommended for children; the maximal dose is 1000mg/day. The adult dose is 400mg twice daily.
   - Education about group A streptococcal infections and the importance of early detection and treatment (this applies both to case and the family members)

CASE MANAGEMENT
(PUBLIC HEALTH)

1. Patient details entered onto EpiSurv and temporary Toi Te Ora ARF spreadsheet register (until regional register available)

2. Ensure there are arrangements for cases to receive long-term penicillin prophylaxis as recommended by the paediatrician or physician
References


18. The National Heart Foundation of New Zealand, Cardiac Society of Australia and New Zealand. Evidence-based, best practice New Zealand Guidelines for