

## **Information on the incidence of Rheumatic Fever in the Bay of Plenty District Health Board region.**

23 July 2010

The Bay of Plenty District Health Board commissioned Dr Belinda Loring to complete a review of the prevalence of acute rheumatic fever in its region in 2008. Dr Loring conducted her study while working as a public health medicine registrar under the supervision of Dr Phil Shoemack, Senior Medical Officer of Health, Bay of Plenty District Health Board.

Attached is a copy of the Loring review and also a document titled "ARF notes" which outlines the agreed plan of action in response to the recommendations made by Dr Loring.

### **Background**

Acute rheumatic fever incidence in New Zealand is higher than most comparable developed nations. Within New Zealand, Māori and Pacific children have even higher rates of disease.

Dr Loring's work, and a similar study completed the following year by Dr George Gray (also a registrar who worked for Dr Shoemack at the time) which focused on the Lakes DHB population, confirmed particularly high rates of rheumatic fever in some communities in the Eastern Bay of Plenty.

*From the executive summary of Dr Loring's review - 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.*

## **Why is the problem so bad in the Eastern Bay of Plenty?**

There is no simple answer to this. We know that the incidence of rheumatic fever is higher among Maori children and in the Eastern Bay of Plenty there are more Maori children than non-Maori children. We know there is a strong link between rheumatic fever and low socio-economic factors, such as poor quality housing, social deprivation and limited access to primary and secondary health care. The Eastern Bay of Plenty is an area which experiences all these factors.

## **Bay of Plenty District Health Board's initiatives to treat and reduce the incidence of rheumatic fever**

The Bay of Plenty District Health Board has responded promptly and comprehensively to the Loring Report which for the first time confirmed the extent of the rheumatic fever problem locally.

The Bay of Plenty District Health Board is currently working with the Primary Health Organisations and its communities across the district in the implementation of rheumatic fever prevention initiatives.

The initiatives completed or currently underway include:

- A general public awareness raising campaign using local media and the by-line "sore throats matter" with the goal being getting parents to take any child with a sore throat to their GP. Toi Te Ora Public Health developed this media campaign which ran very successfully earlier in 2010.
- A targeted awareness raising campaign focused on ensuring Māori receive the "sore throats matter" message. Toi Te Ora Public Health developed a Maori media programme which ran earlier this year and which is incorporated into each of the school throat swabbing campaigns (see below).
- Continuing Professional Development for GPs, practice nurses, district nurses, and hospital paediatric staff (doctors and nurses), bringing to their attention the guidelines developed by the National Heart Foundation for the treatment of sore throats and the diagnosis, treatment, and on-going care of Rheumatic Fever. <http://www.heartfoundation.org.nz/index.asp?pageID=2145881465>.

Several evening CME meetings with GPs in Whakatane and Tauranga have been held in recent months as part of this Continuing Professional Development programme and presentations have been made to clinical staff at both Whakatane and Tauranga Hospitals.

- A school-based throat swabbing programme is being funded by the Bay of Plenty District Health Board in the high incidence communities in the Eastern Bay. The campaign in Opotiki schools started in October 2009 and is being led by Te Ao Hou PHO in conjunction with Whakatohea Health Service. Similar programmes are planned for Kawerau (to commence during the next school term, possibly as

early as August) and Murupara (starting at the beginning of the 2011 school year).

- Reviewing current arrangements for secondary prophylaxis. Each child diagnosed with acute rheumatic fever is given a monthly injection of Penicillin for at least 10 years to prevent a recurrence of the disease and to reduce the risk of chronic rheumatic heart disease. This is usually the responsibility of the local district nursing service.
- Establishing a BOP/Lakes Rheumatic Fever Steering Group. This group is chaired by Senior Medical Officer of Health Phil Shoemack and is the governance group which meets quarterly to provide oversight and direction for all the listed initiatives across BOP and Lakes. Dr Malcolm is a member of this Governance Group.
- Developing a Rheumatic Fever Register to ensure each child diagnosed receives his/her monthly injection of Penicillin and is reviewed regularly in 'outpatients' by a Paediatrician. The Rotorua Area Primary Health Service (RAPHS) has been operating such a register in-house for several years and is now working with Lakes and Bay of Plenty District Health Boards so the register can be used by all relevant health providers across the Bay of Plenty and Lakes districts.
- Strengthening relationships with other agencies, including laboratories, public health units, and paediatricians.
- Involvement with a proposal to pilot echocardiographic screening. Dr Malcolm has been the local advocate and organiser of a pilot of using echo-screening of well children in some Eastern Bay communities. This screening is designed to detect previously undiagnosed cases of rheumatic fever and has been conducted in conjunction with a team led by Dr Nigel Wilson, paediatric cardiologist, from StarShip.
- Improving data quality and reporting.

The Bay of Plenty District Health Board, with Lakes DHB responded promptly and comprehensively once the prevalence of rheumatic fever in their regions was identified.

The Loring report recommendations are being implemented with funding for the initiatives coming from the District Health Boards, the Ministry of Health and Starship Hospital. The Ministry initially provided a small amount of 'seed' funding to get things underway.

BOPDHB has allocated funding for each of the listed initiatives in the region. In addition, Dr John Malcolm was successful in attracting some outside support for the echo-screening programme. The Ministry of Health also funded a community awareness programme undertaken by Lakes DHB.

The Board of the Bay of Plenty District Health Board, the CEO and the Executive all agreed to give this priority for funding and this is evidenced by the DHB's prompt response to the recommendations of the Loring report.

The level of investment and the range of programmes outlined show a high level of organisational support. The CME work with GPs has been focused on ensuring they are fully conversant with the Heart Foundation Rheumatic Fever guidelines. In the hospitals there is strong support from paediatricians and adult cardiologists who are committed to ensuring all cases of rheumatic fever receive the long term follow up they require.

The BOPDHB has been taking a joint approach on developing a better register and better between the register and children with Rh fever and ongoing management of these children, with Lakes DHB.

Rotorua Primary Health Services have adapted a register used for cancer screening for rheumatic fever patients to prevent reoccurrences of acute rheumatic fever through a managed programme of 4-weekly benzathine penicillin injections; to manage paediatric clinic follow-ups; and to monitor rheumatic fever patients as they transition into adulthood.

The register has now been established and Lakes DHB patients are being loaded onto it. When it is completed and any problems have been ironed out, the BOPDHB will begin loading their patients onto it.

The BOPDHB has funded CME training for GPs (and paediatricians), raising general awareness of acute rheumatic fever, and specific training of GPs in the use of the NZ standard algorithms for managing sore throats in primary care. GPs throughout the BOP district have been surveyed on their knowledge and use of the algorithm, which has showed improvements in their correct use.

Better follow-up of young adults by a dedicated adult physician/cardiologist and nurse whose job it is to keep tracking affected adults and ensure they keep healthy is part of the comprehensive Rheumatic Fever Plan for the BOPDHB which is yet to be considered fully.

### **Funding provided for rheumatic fever initiatives**

The Bay of Plenty District Health Board received initial funding from the Ministry (at the DHB's request) of \$69,000 in mid-2009 to initiate rheumatic fever response work.

This followed research released earlier in 2008/09 from Toi Te Ora-Public Health public health medicine registrars showing that the incidence of rheumatic fever in the BOP (and Lakes) DHBs was double what had been notified to the Medical Officers of Health by GPs and paediatricians.

Acute rheumatic fever is a notifiable disease under the Regulations.

This initial funding was used to initiate a BOP/Lakes Rheumatic Fever Steering Group to oversee planning and activity; attend national forums on rheumatic fever; visit Northland where a successful Sore Throats Matter programme has been in operation for many years; development of separate but linked BOP and Lakes rheumatic fever prevention

plans; initial CME for GPs and paediatricians; initial planning for a Sore Throats Matter programme in Opotiki.

The DHB set aside \$261,000 in 2009/10 for rheumatic fever prevention work. This has been fully utilized for:

- The Opotiki Sore Throats Matter school-based throat swabbing programme which began in October 2009. Monitoring of the success of this programme as a template for similar programmes in other towns in the BOP.
- Further CME and community health worker training on rheumatic fever across the BOP district.
- A community-based awareness programme on rheumatic fever across the BOP district.
- Planning and establishment funding for the Kawerau Sore Throats Matter programme beginning in July 2010.
- Planning for the Murupara Sore Throats Matter programme scheduled to begin in February/March 2011.
- Additional laboratory costs for Streptococcus A tests.

The DHB has set aside an increased amount of \$330,000 for 2010/11. This funding will be utilized for:

- Opotiki, Kawerau and Murupara Sore Throats Matter campaigns.
- Continuation of the community-based awareness programme on rheumatic fever across the BOP district.
- Additional laboratory costs for Streptococcus A tests.
- Monitoring and evaluation of work to date.
- Development of BOPDHB component of the Lakes/BOP Rheumatic Fever register.

This level of funding will be expected to continue in future years.

## Attachment 1

### Recommendations for further actions from the Loring Report

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 Kawarau, Opotiki and Murupara.
  - Funding should be available to develop and deliver school-based programmes in these communities, **in collaboration with the communities** and local health professionals.
  - 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

## Summary of key findings from the Loring Report

- 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.