



**Perinatal and
Maternal Mortality
Review Committee**

*He matenga ohore, he wairua uiui,
wairua mutunga-kore*

**Perinatal and
Paediatric Pathology Service
Provision in New Zealand 2008**

**A report by the
Perinatal and Maternal Mortality Review Committee**

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Foreword

Accurate documentation of the reasons for fetal and neonatal deaths allows any changes in cause of perinatal death over time to be analysed and preventability to be assessed. Until recently the cause of death listed on the death certificate has been the cause used by the New Zealand Health Information Service to document and monitor perinatal deaths annually in this country. This practice is concerning given that the certified cause of death can be discordant with the cause of death as determined by case review, in around 50 percent of neonatal deaths (Hunt and Barr 2000).

The Perinatal and Maternal Mortality Review Committee (PMMRC) has been charged with the job of reviewing perinatal deaths in New Zealand. Data collection has commenced and the second annual PMMRC report to be produced in 2008 will include analysis of the first available data, which have been collected from the last six months of 2006. Although a range of clinical data are being collected, in many cases the information most likely to elucidate the main cause of death of any infant is that obtained from the post mortem examination. Without a high consent rate for, and ready availability of perinatal post mortem examinations, the information available to the PMMRC to assign a cause for each perinatal death reviewed will be significantly compromised. Most importantly, as many parents want to know 'the reason why' their baby or child died, a diagnosis based on well-informed analysis is required.

This report has been produced by the PMMRC to discuss provision of perinatal pathology services in New Zealand. Both perinatal and paediatric pathology are sub-specialities of anatomic pathology. Like many services in New Zealand orientated to infants and children rather than adults, access to these services is variable and resources are limited and stretched. This report highlights these issues and makes a number of recommendations to:

- facilitate improved services in the current environment
- ensure that a planned approach is taken to sustain and improve this important clinical service.

The main focus of this report is perinatal pathology services and the recommendations in particular are focused on these services. Paediatric pathology services will also be discussed as they are closely related to perinatal pathology services.

Dawn Elder

Executive Summary

1. Families and whānau in all areas of the country and of all ethnicities should have an equal opportunity to receive a considered and complete investigation after a perinatal death, including appropriate support and follow-up.
2. Post mortem remains the gold standard for clarifying cause of death for the majority of fetal, perinatal, neonatal and infant deaths and provides important information for parents concerning future pregnancies.
3. All families and whānau who experience a fetal or neonatal death should be offered a post mortem examination as part of the investigation of that death. Ideally this service should be provided by a perinatal pathologist.
4. As post mortem examination may not be an acceptable investigation for all families and whānau, guidelines for the investigation of perinatal death must offer alternatives to post mortem. The guidelines must be clear about when these alternatives are likely to provide sufficient information to explain the cause of death and when the information that will be gained will be limited and possibly not contribute to the explanation at all.
5. Perinatal pathology in New Zealand should be a sustainable service, accessible seven days a week. The service should incorporate a national clinical network and build on the strengths of the current model.
6. Because there is a worldwide shortage of perinatal and paediatric pathologists, the best solution to the current shortage in New Zealand is to offer training locally.
7. A training post should be set up in New Zealand for a junior consultant to undertake advanced training in perinatal and paediatric pathology.

The Importance of Perinatal and Paediatric Pathology

Introduction

In 1997–1998 a national review of paediatric specialty services was undertaken and the findings published in *Through the Eyes of a Child* (HFA 1998). This report lists nine principles that should underlie the provision of health services for children and young people. These principles are that services must be:

- child and family focused
- as close to home as possible within the bounds of quality and safety
- provided to achieve equity of outcome
- based on international best practice, research and education
- monitored and evaluated regularly
- integrated with other health services
- culturally safe
- fiscally responsible.

Pathology and laboratory services were addressed in this report. It recommended that paediatric and perinatal autopsies (post mortems) and surgical pathology should be performed by pathologists with appropriate specialist training. A further recommendation was that two or three specialist trained paediatric/perinatal pathologists should be appointed over the next three years.

Utility of perinatal and paediatric pathology

Post mortem remains the gold standard for clarifying cause of death for all age groups but particularly in the perinatal and paediatric age range. The post mortem can confirm clinical diagnoses made before death and contribute new information about the cause of death and associated factors. The information it provides may be important for two reasons.

1. It may significantly change the advice given to families about recurrence risks for a future pregnancy.
2. The clinical knowledge gained from the post mortem can influence how clinicians caring for a woman and her infant manage another similar case.

Local studies have confirmed the utility of expert perinatal autopsy in the New Zealand population. For example, in a review of 56 neonatal deaths over a two-year period 73 percent of those deaths had a post mortem and of those, new clinical information was found in 59 percent (Sanders et al 1999). In addition, in a review of autopsy reports for 29 very preterm infants dying at less than 28 days of age, new findings were made in 79.3 percent of them and significantly changed the diagnosis in 27.6 percent (Elder and Zuccollo 2005).

Overseas studies confirm the utility of post mortem in auditing antenatal diagnosis of fetal anomaly (Amini et al 2006; Sun et al 1999; Scott 2002; Dickinson et al 2007). Although more sophisticated ultrasound techniques aid visualisation and therefore facilitate more accurate diagnoses, continual monitoring of antenatal diagnoses is important especially when they are the basis of decisions to terminate pregnancy (Isaksen et al 2000). Post mortem can refine the estimate of the risk of recurrence of fetal anomaly in 27 percent of cases (Boyd 2004).

Post mortem is critical after fatal perinatal asphyxia. Information obtained from a post mortem may change final diagnoses; for example, it could indicate that the asphyxial insult occurred prior to labour (Becher et al 2004; Elder et al 2005). This potential for providing key information has important implications if concerns are being aired about the clinical practice of those who cared for the mother in labour. This information comes from histological examination of the brain and will not be available from magnetic resonance imaging (MRI) examination.

Placental examination is a critical aspect of a perinatal pathologist's workload. Placental abnormalities can be associated with adverse neurological outcome in preterm and growth restricted infants (Redline et al 2000; Viscardi and Sun 2001). Recognised indications for placental examination are pregnancies with one or more of the following features (RCOG and RCP 2001):

- multiple pregnancy
- small for gestational age infant (below the third centile for age and sex)
- neonatal hypoxic ischaemic encephalopathy
- early neonatal sepsis
- preterm labour less than 34 weeks
- congenital malformations
- macroscopic placental abnormalities
- recurrent antepartum haemorrhage
- clinical chorioamnionitis
- established maternal diabetes
- severe pre-eclampsia.

In a busy obstetric service the need for this examination provides a significant workload for pathology services.

Alternatives to full post mortem examination

There has been concern about decreasing consent rates for post mortem because of controversy over organ retention in the United Kingdom, Australia and New Zealand (Khong and Tanner 2006; Adappa et al 2007). If parents are reluctant to consent to a full post mortem examination, it may be useful to limit a post mortem to taking samples for histology from what is clinically thought to be the most affected organ(s). A limited autopsy will, however, obtain only limited information. The procedure becomes a biopsy after death and significant information may be lost if the organs being assessed cannot be examined fully and tissue samples for microscopy cannot be taken from all organs.

MRI has been considered as a second best alternative to post mortem. MRI can provide good correlation for central nervous system abnormalities but is poor at detecting cardiovascular anomalies. Problems arise with both access to MRI and access to expertise in reporting necropsy MRI (Griffiths et al 2005; Brookes 2006). Histology is not available unless targeted image-guided biopsy is also included in the examination. Computed tomography (CT) scanning of the head has a poor correlation with post mortem findings in infants who have died because of perinatal asphyxia; and routine X-ray is of limited use except in specific cases (Flodmark et al 1980; Olsen et al 2003).

If parental consent is not obtained for post mortem and the fetus or infant is dysmorphic or has evidence of other congenital anomalies, it can be helpful for an expert in dysmorphology to make a clinical examination. Those with expertise in this area are perinatal pathologists or geneticists with expertise in fetal anomalies. Clinical photos should be taken and the infant should be weighed and measured. For some genetic and chromosomal abnormalities a clear diagnosis can be made from blood or other fluid samples taken for genetic testing before or after birth. In such cases post mortem will not always be required to accurately define the cause of death.

The Current Situation of Perinatal and Paediatric Pathology Services

Pathology workforce in New Zealand and overseas

In New Zealand, a perinatal pathology service has developed in an opportunistic, piecemeal fashion and is dependent on the interests and availability of suitably trained pathologists around the country. There has been no specific funding allocated to this service nor has there been formalised specialist training in perinatal pathology in New Zealand. Although the most current workforce analysis published by the New Zealand Committee of Pathologists reports on a number of pathology sub-specialties, it does not mention paediatric and perinatal pathology (New Zealand Committee of Pathologists 2007).

The workload involves performing and reporting post mortems, supervising placental histology reporting, and attending multidisciplinary meetings. Perinatal mortality or education meetings are important forums in which obstetricians and paediatricians discuss cases with the pathologist. These meetings are held in referring institutions on a regular (eg, monthly) basis.

In New Zealand the population ratio is 1 pathologist per 20,000 people (or, in terms of a full-time equivalent (FTE), 1 FTE per 27,877 people). In contrast, in Australia (where there is a severe workforce crisis) the ratio is 1 per 15,925. New Zealand would need another 59 pathologists to reach even Australian levels (New Zealand Committee of Pathologists 2007).

In the United Kingdom there are significant shortages in paediatric and perinatal pathology (Squier and Ironside 2006). In a British study involving 60 consultants from level II and III neonatal units, 40 percent reported they did not routinely offer a post mortem examination and the most common reason for not offering it was lack of availability of a perinatal pathologist (Rose et al 2006).

Auckland

The perinatal workload is shared between an FTE position in Auckland and a 0.6 FTE position (0.4 FTE for the Auckland District Health Board (DHB) and 0.2 FTE for the National Forensic Pathology Service) delivered from Wellington.

The Auckland role includes coverage at Auckland City and Middlemore Hospitals. Specific responsibilities involve:

- the examination of the pregnancy product losses less than 20 weeks gestation
- paediatric surgical pathology including renal biopsies (this load is shared with a general pathologist)
- perinatal pathology at North Shore and Waitakere Hospitals
- attendance at Auckland City Hospital's Maternal Fetal Medicine meeting
- participation in the anatomic pathology 'on call' roster in Auckland.

At North Shore and Middlemore Hospitals, placentas are examined by a general anatomic pathologist unless specifically referred on to a perinatal pathologist.

When undertaking responsibilities for Auckland, the Wellington pathologist's responsibilities include:

- examination of pregnancy losses 20 weeks gestation and over
- post mortem examination of all neonatal and some childhood deaths
- forensic responsibilities in regard to specific deaths
- travel to Auckland two to three times a month for mortality meetings; if appropriate, post mortems may be carried out during this time
- attendance at Paediatric Intensive Care Unit and cardiac mortality meetings
- attendance at the monthly Auckland City and Middlemore Hospital's perinatal mortality meetings.

The Wellington specialist pathologist makes herself available seven days a week to facilitate a prompt service (see Appendix 3 for views of parents). Her responsibilities specific to Wellington are outlined below.

Clearly the above schedule of responsibilities involves considerable travel for the expert Wellington perinatal/paediatric pathologist. Although service responsibilities have been well organised, such a schedule relies on the commitment and positive relationship of a very small group of individuals. In addition there is a need to transport deceased infants from Auckland City and Middlemore Hospitals to Wellington for post mortem.

Wellington

The Wellington-based perinatal/paediatric pathologist is responsible for service locally and also takes referral from other DHBs. These responsibilities include:

- responsibility for the fetal and perinatal workload at Wellington and Hutt hospitals
- supervision of 'sign-out' of all placental histology reports
- provision of DHB perinatal pathology services for MidCentral, Waikato, Rotorua, Tauranga, Gisborne, Whanganui, Masterton, Taranaki, Hawke's Bay, and Nelson Marlborough DHBs when requested
- attendance at mortality meetings at Hutt Valley, MidCentral and Hawke's Bay DHBs at intervals of three to four months
- monthly PowerPoint presentations of cases for Waikato meetings
- attendance at other DHBs as required/on demand.

These services are provided seven days a week.

In addition, time is contracted to the National Forensic Pathology Service as noted above in relation to Auckland. This workload involves attendance at coroner's inquests and court proceedings over a wide area of the North Island.

Christchurch

At Christchurch Hospital until recently, a general trained anatomic pathologist, with an interest in perinatal and paediatric pathology provided the perinatal pathology service. More recently a perinatal and anatomic pathologist joined the service. However, this specialist pathologist is predominantly involved in the adult surgical pathology service and participates in the anatomic pathology roster at Christchurch Hospital. Canterbury DHB also provides services to Timaru, Ashburton and the West Coast.

Dunedin

Until early 2007 a specialist perinatal pathologist provided a service in conjunction with providing clinical time to adult surgical pathology services at Otago DHB. Since early 2007, when the DHB laboratory service was restructured, the specialist perinatal/paediatric pathologist has provided a perinatal/paediatric service under a separate contract from the private laboratory provider. In addition to this service, this specialist pathologist provides extra work for forensic cases and does occasional locums in adult surgical and autopsy pathology around South Island laboratories. Cases in Oamaru and Central Otago also receive expert services by this specialist. However, most Southland DHB cases are performed by a general anatomic pathologist at that site.

It needs to be noted that as a result of the restructuring of Otago DHB laboratory services, perinatal services were almost lost. It would appear that without the strong case presented by key clinical stakeholders, this important element of laboratory services would have been lost.

Perinatal workload

Preliminary information from PMMRC data collection suggests that there may be up to 700 perinatal deaths per year. If 75 percent of these deceased infants were referred for post mortem, this would represent a workload of 525 cases per year. Each post mortem is at least eight hours of work. Therefore two full-time equivalent perinatal pathologists would be required just to do this number of post mortems without any time allocated to mortality meetings, teaching or research, or review of placental histology. This volume excludes referral for post mortem of infants dying after 28 days of age and referral for examination of fetuses dying before 20 weeks gestation.

When assessing perinatal workload, placental examination also needs to be taken into account. Larger tertiary centres will assess up to 400 to 500 placentas a year.

Based on this conservative estimate, the current workload is unsustainable. There is no visible acknowledgement from DHBs of the need for succession planning in this key sub-specialty service.

Issues for Perinatal and Paediatric Pathology Services

Issues related to recruitment

Due to the worldwide shortage of perinatal and paediatric pathologists, any response to the problem in New Zealand will need to include:

- provision of local training in perinatal and paediatric pathology
- strategies to attract suitably qualified pathologists from overseas.

Trainees in pathology who are advanced in New Zealand are the likely source of our future perinatal pathology workforce. However, if recruitment is to be successful, a sustainable position with appropriate supports will need to be offered. For a career in perinatal pathology to be considered by these trainees, there is a need for:

- the colleges to clearly identify the sub-specialties of paediatric and perinatal pathology and to offer opportunities for training and accreditation in these specialties
- remuneration at consultant level to be competitive with remuneration rates for anatomic pathologists working in private or in a combined public-private environment
- a nationwide perinatal/paediatric pathology service with a national 'on call' service in place so that no single pathologist is the only person providing a seven-day service.

Can the work be done by anatomic pathology specialists?

There are many reasons why paediatric and in particular perinatal pathology requires expertise and experience different from that appropriate for general adult anatomic pathology. These reasons include the following.

- The range of diseases being assessed, especially those that are genetic, congenital and metabolic in aetiology, is different.
- Many of the malignancies that present in childhood are different from those seen in adult medicine.
- An understanding of normal developmental changes and perturbations of embryology is required.
- Preparation of the necessary samples, such as those taken when investigating possible inborn errors of metabolism, can require special care.
- Different surgical techniques are used in autopsy on fetuses, infants and young children. These can be critical as parents frequently want to have the body of their infant or child at home after the post mortem.

- Paediatric and perinatal pathology services are essential to support secondary, tertiary paediatric, neonatal and obstetric care. These services care for patients in an age group where the effect of any pathological process on the developing child can differ from the effect of the same process on the mature adult.
- There are separate textbooks, journals, meetings, courses, exams and quality assurance processes, also indicating that the issues are different.

Post mortem examinations performed by specialist perinatal pathologists in regional centres are more likely than those completed in non-regional centres to conform to minimum standards (92–100 percent compared with 28–69 percent) and to yield additional information (Cartlidge et al 1995; Vujanic et al 1998). Expertise in placental histological examination is also important as general surgical pathologists may fail to recognise the clinical relevance of placental lesions (Hargitai et al 2004). The Clothier report (Clothier et al 1994) recommended specialist paediatric pathology in all cases of unexpected or clinically unaccountable death in children.

In many areas of New Zealand, histological reporting on paediatric pathology specimens is included in the general pathology services workload. This arrangement works well in many areas. There are also areas in New Zealand where in the past anatomic pathologists have performed post mortems locally because there was no alternative specialist service. These practitioners are now referring these cases on for specialist attention. These referrals have significantly increased the workload of the specialist perinatal pathology service.

What is the current efficiency and effectiveness of the service?

The current service is under considerable strain. Although a high-quality service is being provided, mainly by a single experienced practitioner, for the majority of the age-related population in New Zealand, there is no 'on call' sustainable service for perinatal pathology. The seven-day service is dependent on the goodwill of this one practitioner and it is not sustainable.

The target gold standard post mortem rate is 75 percent for perinatal deaths. This rate is near to being achieved in Wellington but not in other centres. Since there has been a regular perinatal pathology service in Auckland provided by Capital & Coast DHB, pathologist post mortem rates have increased significantly. Further increases in referrals indicate a more robust approach to the investigation of perinatal death but this change has also increased pressure on an already over-stretched system.

To be effective a perinatal pathology service must be embedded in the core services for which it provides clinical information, such as the obstetric, paediatric and genetic services of the referring organisation. Some families and whānau may find it helpful to meet the perinatal pathologist prior to consenting to the procedure (see Appendix 3). These interactions are not possible when the perinatal service is based away from a tertiary centre. Over 50 percent of deceased infants who are currently transported to Capital & Coast DHB for post mortem come from a centre with tertiary obstetric and neonatal services that should expect to be supported by a local perinatal pathology service.

The current schedule is absolutely dependent on the commitment, expertise and goodwill of a very small number of individuals and is exceedingly vulnerable. There is an urgent need to provide a national approach to the planning of perinatal pathology services for New Zealand. Such an approach should incorporate the successes of the current process and provide for an expanded service aligned to the clinical demands of the relevant population.

One demonstration of the effects of the current tensions is that the overload of a fragmented (national) system results in delays in final reports for post mortem examinations. It is distressing for parents when they return for follow-up after the death of an infant and the final post mortem results are not available.

In addition, as post mortem reports take priority, signing out of placental histology reports on live-born infants may be delayed. Sometimes knowledge of the placental histology may have implications for the care of a live-born infant with significant postnatal problems, but this information may not be available in a timely manner. From a risk management perspective such delays are unacceptable and avoidable.

Issues related to training

The website and manual of the Royal College of Pathologists of Australasia do not recognise perinatal pathology as a sub-specialty in any obvious way. On the website, seven career pamphlets are advertised, covering microbiology, genetics, anatomical, haematology, immunopathology, chemical and forensic but not perinatal or paediatric pathology (<http://www.rcpamannual.edu.au>).

This matter is currently under discussion within the college, specifically within the Paediatric Pathology Group of Australia and New Zealand. These discussions will involve addressing training and accreditation of post-fellowship trainees wishing to pursue a career in paediatric and perinatal pathology.

Recommendations for Provision of Perinatal and Paediatric Pathology Services

Changes that can be made immediately and be effective immediately

Recruitment

- Create a senior registrar / junior consultant training post in Capital & Coast DHB from 2009 to assist and support the onerous workload cover and 'on call' support in Wellington.
- Re-advertise a full-time Auckland perinatal pathology position.

Retention

- Arrange locum support to enable accrued annual leave to be taken by the perinatal pathologist.

Effectiveness

- Develop national guidelines for referral to ensure the information that the pathologist requires for post mortem is relevant and appropriate.

Efficiency

- Ensure appropriate administrative support is available to enable reports to be released in a timely manner.

Changes that can be made immediately but will take three to four years to show an effect

Recruitment

- Set up a senior registrar / junior consultant training post based initially at Capital & Coast DHB with the support of the Royal College of Pathologists of Australasia. This post should involve a two-year training programme that comprises six months based in Wellington (focusing on perinatal pathology), six months in Auckland (focusing on perinatal and paediatric surgical pathology) and one year of overseas experience.
- Ensure the Royal College of Pathologists of Australasia recognises perinatal and paediatric pathology as a sub-specialty area and that workforce coverage is monitored through a national plan.

Retention

- Ensure remuneration is competitive with other pathology sub-specialities.
- Ensure an appropriate national roster system is in place so that no single perinatal pathologist is always on call.
- Ensure training is appropriate and clinical support services are in place.

Effectiveness

- With all DHBs undertake a full assessment of workload, identify the FTEs required and develop a long-term succession planning process that includes predictors based on an increased referral rate for perinatal post mortem and placental histology assessment.
- Reconfigure organisation of the service to be a nationwide service using the framework of a national clinical network.

Efficiency

- Align perinatal death support services so that clinicians using perinatal pathology services are competent in issues of consent for post mortem and in providing feedback regarding post mortem results to families.

Outcomes sought

- Fully supported perinatal and paediatric pathology services should be available in Wellington.
- Fully supported paediatric and perinatal pathology services should be available in Auckland.
- Fully supported perinatal pathology services for the South Island could be centralised to a single location.

Appendix 1: The Scope of Perinatal and Paediatric Pathology

In its multidisciplinary review of fetal, perinatal and paediatric pathology services in the United Kingdom, the Royal College of Paediatrics and Child Health (RCPCH) states that 'pathology and histopathology services for children should be provided in the long term only by paediatric pathologists and those with relevant specialist expertise' (RCPCH 2002, p 7). Services should be concentrated at specialist sites, paediatric pathology should not be subsumed into other pathology services, and action to preserve and develop services requires government and professional colleges to recognise the critical importance of the service.

The Tertiary Services Review published by the New Zealand Paediatric Society in 1998 emphasises that health care for children should be provided by professionals trained in looking after children. The society concurs that it would be 'illogical' not to carry this principle into paediatric services after death (PSNZ 1998).

Paediatric pathology

'The scope of paediatric pathology is defined by the age of the patients and not by the disease or organ affected' (RCPCH 2002, p 8). Paediatric pathology includes clinical services, teaching, research, audit, and the setting of standards and protocols (RCPCH 2002). It involves autopsy, forensic medicine and surgical specimen histology. A post mortem examination may include gross anatomical and histopathological examination, histopathology and molecular biology, photos, X-rays and MRI.

All these functions require paediatric pathology to be embedded in expert radiology, cytogenetics and other laboratory services.

Perinatal pathology

The knowledge and skill set required to practise in perinatal pathology differ from those required for paediatric pathology alone. The perinatal pathologist must have expertise in dysmorphology and be familiar with embryology and the changes occurring in the developing fetus. As many stillborn fetuses die some time before delivery, perinatal pathologists must be able to distinguish abnormalities due to post mortem change from true physical findings.

The scope of perinatal pathology includes examination of fetal deaths taking place at or after 20 weeks gestation and neonatal deaths up to 28 days of life. It includes examination of fetuses of less than 20 weeks gestation. Termination of pregnancy is another important reason for post mortem as part of clinical audit of antenatal diagnosis. Perinatal pathology also includes examination of the placenta, after either live birth or fetal death.

Appendix 2: Perinatal Pathology Workshop

In October 2007 a workshop was held in Wellington to discuss issues around the provision of perinatal pathology services in New Zealand. All pathologists practising perinatal pathology in New Zealand were present. Specifically the aim was to set an action plan detailing how to increase, sustain and support perinatal pathology services in New Zealand. This plan and the attendees at this workshop are listed at the end of this appendix.

The chair set the scene with a discussion of the role of perinatal pathology and the current workload issues in perinatal pathology in New Zealand. Dr Jeannette McFarlane then tabled a letter summarising some of the current workload issues in New Zealand. She emphasised that on the retirement of Dr Zuccollo it is unlikely that anybody would be available to take on Dr Zuccollo's current workload without some serious workforce planning. If no one took on the workload, it would mean cutting services in Auckland, Wellington and, because of Dr Zuccollo's role nationally, in most of the North Island secondary perinatal centres. Such cuts would create a big gap in provision of perinatal and paediatric forensic pathology services locally, regionally and nationally. Dr McFarlane emphasised the importance of providing training in perinatal pathology locally to solve this impending workforce crisis, given the past experience of difficulty in filling perinatal and paediatric pathology positions in Auckland.

The other pathologists present also talked individually about the services provided in their area. In the South Island providing perinatal pathology services is currently not sustainable unless they are involved in anatomic pathology.

Dr Nick Baker, representing the Paediatric Society of New Zealand, gave a presentation on a Framework for Sustainable Nationwide Services for Children and Young People in New Zealand. The aim is to apply this framework to a number of tertiary specialities that serve the infant and paediatric population of New Zealand. The model requires a cross-DHB approach to the provision of services and thus centralised national planning. Examples of services where this approach has been or is to be applied are paediatric oncology services and paediatric rheumatology services. Perinatal pathology services are an ideal fit for this sort of model. The national forensic services model has been suggested as a guide to planning a national perinatal service.

Vicki Culling, a PMMRC member, presented information on the transportation of deceased fetuses and infants referred for post mortem at another DHB. Some effort has already gone into developing protocols for air travel for deceased infants, including the development of a carrycot with an inbuilt cooling device. Despite concerns about the need for travel of infants for post mortem, this practice appears not to have deterred families from consenting for the procedure as perinatal post mortem rates at Auckland and Middlemore Hospitals have increased since a service has been provided in Wellington. The most likely reason for this increase is the perceived value of the clinical information provided by the specialist pathologist at the monthly perinatal mortality meetings when post mortem results have been presented.

There was some discussion about DHB planning and funding processes. It is clear that perinatal pathology services fall under the radar of the majority of DHBs in the country. Visibility of the service is a significant issue. Funding for perinatal pathology positions could be based on a combined model with input from DHBs and forensic services, as well as from universities in view of their teaching and research function.

The rest of the workshop focused on discussion about ways of resolving these issues. A combined approach is required with support from individual DHBs, District Health Boards New Zealand, the professional colleges, the Ministry of Health and the Clinical Training Agency. These agencies also need to be reliably informed about the nature of problem. This report highlights the issue and proposes solutions. The Clinical Training Agency has indicated that support can be provided for a training position if the need is documented.

Action plan

The following plan was tabled to progress the issues discussed. It was determined that:

1. a report of the meeting and the issues of concern be presented
2. discussions be held with the Royal College of Pathologists of Australasia about training
3. the matter be raised with the Council of Medical Colleges

4. an exercise be undertaken to job-size perinatal and paediatric pathology workload as accurately as possible
5. more detail be developed around a plan for a national network of perinatal services
6. a parental viewpoint be presented and considered.

Progress as at June 2008 aligned to the above points.

1. This report represents a completion of task 1.
2. Discussions are in progress within the college on training.
3. Feedback has not yet been received from the Council of Medical Colleges.
4. Some work has been done on job-sizing but more detail is required.
5. There is 'work in progress' with the Ministry of Health to progress the planning of national clinical networks.
6. A parental viewpoint has been sought and is profiled in Appendix 3.

Workshop attendees

Dawn Elder (Chair of Workshop), Paediatrician, Capital & Coast DHB; Committee Member, PMMRC

Vicki Culling, National Coordinator, Sands; Committee Member, PMMRC

Nick Baker, Community Paediatrician, Nelson Marlborough DHB; President of Paediatric Society; Committee Member, Child and Youth Mortality Review Committee

Jane Zuccollo, Perinatal Pathologist based in Capital & Coast; also employed by Auckland DHB and National Forensic Pathology Service

Mollie Wilson, Hawke's Bay DHB; Committee Member, PMMRC

Jeannette McFarlane, Paediatric and Perinatal Pathologist, LabPlus, Auckland

Jerzy Stanek, Pathologist, Canterbury DHB

Andrew Campbell-Stokes, Technical Advisory Services (TAS)

Janice Donaldson, Senior Portfolio Manager, SIG, DHBZ

Noelyn Hung, Pathologist, Dunedin

John Marwick, Ministry of Health (for part of the meeting)

Gillian Bohm, Principal Advisor, Quality Improvement and Audit, Ministry of Health; PMMRC Secretariat

Faith Roberts, Senior Policy Analyst (committees), Quality and Safety, Ministry of Health; PMMRC Secretariat

Apologies

Cindy Farquhar, Chairperson, PMMRC, Postgraduate Professor of Obstetrics and Gynaecology, University of Auckland, Auckland

Judge Neil MacLean, Chief Coroner

Lesley McCowan, Associate Professor Obstetrics & Gynaecology; Committee Member, PMMRC

Simon Stables, Head of National Forensic Pathology Service

Martin Sage, Regional Forensic Pathologist, Christchurch

Deborah Harris, Nurse Practitioner, Waikato Neonatal Unit; Deputy Chair, PMMRC

Appendix 3: The Family Perspective

The death of a child, infant, newborn or fetus is a major life event for any family unit and in particular for the parents of the child. At the time of the death, it can be difficult for parents to fully comprehend the processes necessary to enable a full understanding of the reason or reasons why their child died. At a six-week follow-up review, emotions relating to the death will be less raw and the parents will have many questions to ask.

It is important that the perinatal services provided for the family at the time of the infant or fetal death are expert and inclusive so that enough information will be available to answer those questions. To provide this level of service, those providing services must have a full understanding of the investigations that it is appropriate to request and of how to guide the family through the consent process.

Māori and Pacific families

For families of any ethnicity, giving consent for a post mortem examination for their deceased infant is a very significant decision. The issue is particularly significant for Māori and Pacific families.

From a review of 10 years of neonatal deaths at Wellington Hospital, it was found that consent rates by ethnicity were 71 percent for Caucasian and other groups, 50 percent for Māori and 35 percent for Pacific families. Māori families were more likely to consent to a post mortem examination when their infant was nearer term than when very preterm (Wong et al 2008). These results suggest that Māori families may be more willing to consent to post mortem examination when cause of death is less clear and less expected.

In a review of causes of late fetal death over the period 1980–1999, post mortem rates fell by 23 percent (from 53 percent to 41 percent) (Craig et al 2004). Māori and Pacific babies and those in more socioeconomically deprived areas, as defined by the New Zealand Deprivation Index, were significantly less likely to undergo post mortem. For these families, these findings represent an inadequate investigation of the fetal death.

An important issue for Māori is access to their deceased infant. Consent is therefore much more likely if the post mortem can be done in a timely manner. Timeliness means provision of perinatal pathology services seven days a week, throughout the working day and sometimes into early evening.

A viewpoint from bereaved families

Sands (Stillbirth and Newborn Death Support) New Zealand is a voluntary, parent-run, non-profit organisation set up to support parents and families who have experienced the death of a baby. Most members/supporters are also bereaved parents. Sands New Zealand has provided the following commentary from bereaved parents about their experiences of perinatal pathology services in New Zealand².

Recognition of the need for a trained, specialist perinatal pathologist in New Zealand is certainly not restricted to health professionals and policy makers. Parents, families and whānau who experience the death of a baby are the 'consumers' or 'clients' of such a service and from our collective experiences we want to support the call for funding for a specialised perinatal pathology training position in New Zealand.

As bereaved parents of babies who have died at various gestations and ages and under various circumstances, the Sands community is regularly faced with the minimisation of our babies' lives and the lesser expectations of services concerned with perinatal mortality. We welcome this opportunity to add our voices to the call for specialist perinatal pathology services and acknowledge the significance and importance of speaking on behalf of future parents and families who will experience the death of a baby and look for answers as many of us have done.

It is important to acknowledge the context within which these decisions are being considered. We are aware that historically there have been negative professional perceptions of the value of perinatal pathology and we are also aware of the workforce crisis facing pathology in New Zealand and the calls for immediate action in the training

² Comments have been used with permission of the parents.

and retention of all specialist pathologists throughout the country. Having acknowledged those issues, we remain committed to supporting the funding of a specialist perinatal pathologist, based on our own varied experiences and further that call to include the need for thorough training and information on perinatal pathology for all medical [maternity] staff.

Families in the Sands community have faced a variety of experiences in regards to pathology; indeed, many of us have had firsthand experience of not receiving specialist perinatal pathology care:

... the main thing that was really hard was when our baby was returned to us she had major damage from the autopsy on her forehead and also the Funeral Director advised us not to undress her as she apparently had a lot of areas behind her head and back that had also been damaged ...

...when he left us to have the post mortem he was dressed in a gown and nappy, showing no skin tears or damage. When he was returned to us there was skin damage on his forehead and more on his chin, he didn't have a nappy on and his gown was stained with seeping fluid. It was devastating to see him like that; I wanted to know what they had done with him, how the damage happened, who didn't think to put a nappy back on him. To the professionals it seemed as if he was just another dead baby, to us he was our son who deserved more respect ...

These babies were not seen by a specialist perinatal pathologist. The babies' parents have been left with unwelcome memories and potential regrets due to the way their babies were treated. Admittedly, a baby's death is exceptionally tragic and circumstances can be trying but there are no valid reasons why their families should be treated any differently than other groups who experience death. Our babies deserve care and respect as do our bereaved parents and families.

Many parents faced with the death of their baby are also faced with their first immediate experience of death. Unsurprisingly, they have preconceptions about the post mortem which can be allayed by specialist provision of services and thorough information being presented:

... to be honest I didn't have any idea what a post mortem really meant, I mistakenly thought it was some very unnatural act that they wanted to do on my son ... I believe that if the process was explained more I might have given it more consideration ... [this parent chose not to have a post mortem performed]

... we felt that the autopsy was really important when our baby died although initially struggled with the thought of what they would do to our baby ...

... I can't really remember a lot about making the decision to have it done or anyone explaining much to us about it at all. I think we just kept asking why it happened and it was suggested that we do it to get some answers ...

... however a post mortem was offered, and being under the influence of heaps of morphine and in shock, I agreed at the time ... I wished someone had discussed with us why a post mortem was to be done as our baby's condition has already been diagnosed ...

... we were asked if we would like a post mortem by our midwife. We didn't hesitate to say yes as we really wanted to know why or how he had died. However, we had no idea what the pathologist would do, who they were, where they do it, who actually handled our baby, except that he'd be away for about 6 hours. It was a very long wait ...

Parents and families want to make decisions based on all possible information; this includes the decision to have a post mortem undertaken on their baby. Health professionals still feel the need to 'protect' us and shield us from further pain. We appreciate the sentiments behind this notion but recommend transparency and the provision of as much information as possible. If we choose to have a post mortem done on our baby, we want to know that the best possible person is doing it and that the results will be the best possible. We want information '... explained carefully, not glossed over or the judgement made that we were idiots or might be upset ...'

Parents are faced with incredibly hard decisions at a tragic and often traumatic time. It is unacceptable to have inconsistent and arbitrary care of our deceased babies – and cruel that some parents consider themselves ‘lucky’ to have had only minimal care. Misinformation and inconsistency still prevail throughout our hospitals:

... yes I regret having a post mortem with Noah. This is only because of the way we were treated on the day Noah was born. I had 15 minutes with my son, was told I could not bath him, dress him, take clay imprints of his hands and feet etc ...

... we went to our 8 week follow-up appointment to be seen by a complete stranger, as the registrar we had seen at the diagnosis of death was on leave, only to be told there weren't any results available yet when we asked about the post mortem. The registrar contacted the pathologist's office and we were then asked if we were sure we had a post mortem completed on our baby as they couldn't find any record of our baby. They did eventually find the records after searching under my name, not my baby's name (he was not registered and didn't have his own NHI number), however the reports were not completed. We left shattered and heart-broken, none the wiser as to what was going on. We were rung a few days later which just happened to be Christmas Eve and told the post mortem showed 'No Cause of Death Identified', and the results would be sent out in the mail. What a wonderful Christmas Present this was to be. To this day 6½ years later I still have not a medical person sit down with me and explain the results or its technical jargon, and yes I lodged a formal complaint about the appalling service we received ...

When a bereaved family has had their baby taken care of by a perinatal pathologist, the difference is clear:

... the post mortem proved that it shouldn't happen again, so this eased my mind. Also, the care and respect with which they treated both us and our daughter made me feel that we had made the right decision. Our daughter died in 2004, but just recently, after emailing [the pathology] department, I have received the very precious photos that were taken before her post mortem. These photos mean I have three new, very precious memories, of my daughter.

... The specialist perinatal pathologist took wonderful care of Noah. When he came home I undressed him and looked at him and could see the care that was taken with him. I will forever be grateful to the perinatal pathologist for this. I called the perinatal pathologist shortly after Noah was born and said that the hospital had only given me one photo of Noah and did she have any I could have. The perinatal pathologist had a long conversation with me answering all my questions about Noah and Hope. After asking about and describing Hope to her, she told me that Hope would have had [condition] also. That is a question that I always believed we would never know the answer to. The perinatal pathologist then forwarded on to me two photos of Noah which I treasure. I also emailed the perinatal pathologist several months later asking her more questions about [condition] and she emailed me a long and detailed letter back. The perinatal pathologist truly cares about these babies and their families. As I said, I will be eternally grateful to her. Yes I regret having the pm done ... but I am so grateful it was the perinatal pathologist who performed it as I have heard many stories about babies coming back in states where you can see that no care was taken. I don't know what I would have done if this had happened to Noah ...

We are lucky to have a family-centred, skilled, expert perinatal pathologist in New Zealand and we should seize the opportunity to have other pathologists trained under her. Through such expertise, we can ensure that expert skills in clinical and psychosocial practice are continued in New Zealand.

Some parents will always choose to have a post mortem for the sake of their future children, and for this reason alone we need expert skills and experience in order to establish any possible answers for the deaths of our babies and ensuring the best outcome for our future children:

... the best news was that it was nothing genetic that she died from which was a huge relief as she was our first baby and we wanted to get as much information as possible to help us when we decided to have another baby ...

... I now have two girls and wonder whether my very naive decision not to have a post mortem will somehow have an effect on them if they go on to have children ...

... I used to wish we hadn't had it done for the fact that it gave us no definite results, but have come to realise that by having it done it ruled out any genetic disorders or other problems that may occur so therefore in a roundabout way we did get some answers – just not the ones we wanted ...

... I needed to know if what had happened with C was going to happen with any other child I would conceive. The post mortem proved that it shouldn't happen again, so this eased my mind ...

As a community of parents and families who have experienced one of life's hardest challenges, we are aware of the potential for good practice and the positive effect it would have on those families who are yet to go through the tragedy of perinatal death:

... if there was a specialist perinatal pathologist in all of our major hospitals available to sit down with families prior to the post mortem so you could meet them, have explained if you wish what they were going to do, that they would be doing the procedure themselves, and return your baby to you with a brief initial finding to be followed up at a later meeting at the conclusion of all results, [it] would be fantastic. This would help eliminate some of the added grief, anger and stress at an already traumatic time of families' lives ...

Sands cannot speak for all bereaved parents and families of babies that have died in New Zealand. However, we do see, or have contact with, a great number of bereaved families throughout the country and therefore speak with 'authority' on the topic. We are hopeful that the addition of parents' and families' voices to the report will help to secure the necessary funding for specialist perinatal pathologist positions in New Zealand.

Workshop Report References

Adappa R, Paranjothy S, Roberts Z, Carlidge PHT. 2007. Perinatal and infant autopsy. *Arch Dis Child Fetal and Neonatal Ed* 92: F49–50.

Amini H, Antonsson P, Papadogiannakis N, et al. 2006. Comparison of ultrasound and autopsy findings in pregnancies terminated due to fetal anomalies. *Act Obstet Gynecol* 85: 1208–16.

Becher JC, Bell JE, Keeling JW et al. 2004. The Scottish perinatal neuropathology study: clinicopathological correlation in early neonatal deaths. *Arch Dis Child Fetal and Neonatal Ed* 89: 399–407.

Boyd PA, Tondi F, Hicks NR, Chamberlain PF. 2004. Autopsy after termination of pregnancy for fetal anomaly: retrospective cohort study. *BMJ* 328: 137.

Brookes JS, Hagman C. MRI in fetal necropsy. *J Magn Reson Imaging*. 2006 Dec;24(6):1221-8.

Carlidge PH, Dawson AT, Stewart HF, Vujanic GM. 1995. Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths. *BMJ* 310: 155–8.

Clothier C, MacDonald A, Shaw D. 1994. *Independent Inquiry relating to Deaths and Injuries on the Children's Ward at Grantham and Kesteven General Hospital*. London: HSMO, pp 128–9.

Craig ED, Stewart AW, Mitchell EA. 2004. Causes of late fetal death in New Zealand 1980–1999. *Aust NZ J Obstet Gynaecol* 44: 441–8.

Dickinson JE, Prime DK, Charles AK. 2007. The role of autopsy following pregnancy termination for fetal abnormality. *Aust NZ J Obstet Gynaecol* 47: 445–9.

Elder D, Zuccollo J. 2005. Autopsy after death due to extreme prematurity. *Arch Dis Child Fetal Neonatal Ed* 90: F270–2.

Elder D, Zuccollo J, Stanley T. 2005. Neonatal death after hypoxic ischaemic encephalopathy: does a post mortem add to the final diagnoses? *Br J Obstet Gynaecol* 112: 935–40.

- Flodmark O, Becker LE, Harwood-Nash et al. 1980. Correlation between computed tomography and autopsy in premature and full-term neonates that have suffered perinatal asphyxia. *Neuroradiology* 137: 93–103.
- Griffiths PD, Paley MN, Whitby EH. Post-mortem MRI as an adjunct to fetal or neonatal autopsy. *Lancet* 2005; 356:1271-1273.
- Hargitai B, Marton T, Cox PM. 2004. Examination of the human placenta. *J Clin Pathol* 57: 785–92.
- HFA. 1998. *Through the Eyes of a Child: A national review of paediatric specialty services*. Wellington: Health Funding Authority.
- Hunt R, Barr P. 2000. Errors in the certification of neonatal death. *J Paediatr Child Health* 36: 498–501.
- Isaksen CV, Eik-Nes SH, Blaas H-G, Torp SH. 2000. Fetuses and infants with congenital urinary system anomalies: correlation between prenatal ultrasound and postmortem findings. *Ultrasound Obstet Gynecol* 15: 177–85.
- Khong TY, Tanner AR. 2006. Fetal and neonatal autopsy rates and use of tissue for research: the influence of ‘organ retention’ controversy and new consent process. *J Paediatr Ch Health* 42: 366–9.
- Maternal, Perinatal and Infant Mortality in South Australia 2005. December 2006 <http://www.health.sa.gov.au/pehs/pregnancyoutcome.htm>
- New Zealand Committee of Pathologists. 2007. *Workforce Analysis: Pathologists in New Zealand*. URL: <http://www.rcpanz.org.nz> Accessed 12 October 2007.
- Olsen OE, Espeland A, Maartmann-Moe et al. 2003. Diagnostic value of radiography in cases of perinatal death. *Arch Dis Child Fetal and Neonatal Ed* 88: F521–4.
- Perinatal Statistic in Western Australia, 2005. 23rd Annual Report of the WA Midwives’ Notification System, January 2007. URL: http://www.health.wa.gov.au/publications/subject_index/h/health_stat.cfm
- PSNZ. 1998. A national review of paediatric specialty services – through the eyes of a child. Paediatric Society of New Zealand & Health Funding Authority. URL: <http://www.paediatrics.org.nz>
- Redline RW, Wilson-Costello D, Borawski E et al. 2000. The relationship between placental and other perinatal risk factors for neurologic impairment in very low birth weight children. *Pediatr Res* 47: 721–6.
- Rose C, Evans M, Tooley J. 2006. Falling rates of perinatal postmortem examination: are we to blame? *Arch Dis Child Fetal Neonatal Ed* 91: 465.
- RCOG, RCP. 2001. *Fetal and Perinatal Pathology*. Report of a Joint Working Party. London: Royal College of Obstetricians and Gynaecologists and Royal College of Pathologists.
- RCPCH. 2002. The future of paediatric pathology services. London: Royal College of Paediatrics and Child Health.
- Sanders T, Zuccollo J, Elder D. 1999. Review of Neonatal Pathology at Wellington Hospital 1996–1998. Oral presentation, New Zealand Perinatal Society meeting, Wellington.
- Scott JES. 2002. Fetal, perinatal, and infant death with congenital renal anomaly. *Arch Dis Child* 87: 114–17.
- Squier W, Ironside J. 2006. Falling necropsy rates and risks to public health. *Arch Dis Child* 91: 551–3.
- Sullivan E & Hall B 2007. Maternal deaths in Australia 2003 – 2005. Maternal deaths series no. 3. Cat. No. PER 42 Sydney: AIHW National Perinatal Statistics Unit.
- Sun C-CJ, Grumbach K, DeCosta DT, Meyers CM, Dungan JS. 1999. Correlation of prenatal ultrasound diagnosis and pathologic findings in fetal anomalies. *Pediatr Dev Pathol* 2: 131–42.
- Vujanic GM, Cartlidge PH, Stewart JH. 1998. Improving the quality of perinatal and infant necropsy examinations: a follow up study. *J Clin Pathol* 51: 850–3.
- Wong A, Elder D, Zuccollo J. 2008. Changes in cause of neonatal death over a decade. *NZ Med J* in press 121(1277): 39-46.

*Heoi anō, kāore he take
o ēnei kōrero ki te kore
te reo kei roto i
te māngai o te iwi*