

29 June 2018

Sophie Dunstone
Committee Secretary
Department of Health

E: stillbirth.sen@aph.gov.au

Dear Ms Dunstone,

**Re: Invitation to submit to the Senate Select Committee on Stillbirth Research
And Education Inquiry**

Thank you for asking the Royal College of Pathologists of Australasia (the College) to comment on this important issue. In general, the College's comment is that autopsies are absolutely vital to Stillbirth research and education however they require highly specialised pathology services and are severely under-funded and under-resourced in Australia.

The following are the College's specific responses to the committee's terms of reference:

The future of stillbirth research and education in Australia, with particular reference to:

- a) consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;

The consistency and timeliness of data availability depends upon the consistency and timeliness of the performance of perinatal autopsy. Consistency is best achieved if the autopsies are performed by Paediatric pathologists with expertise in the area of perinatal pathology. This requires centralised services as there is a very limited number of Anatomical Pathologist with training, expertise and interest in this area.

Centralising the service requires organisation and funding for transportation to and from a central Department, a liaison officer to co-ordinate the transfer, mortuary staff to receive the bodies and undertake the preparation for the autopsy, the Pathologists to perform the autopsy with a trainee Pathologist (Registrar) to ensure expertise is available in the future. Administrative staff are required to prepare and type the reports, laboratory staff to process the required blocks and slides and Pathologists and trainees to examine the slides, correlate all the information (clinical, autopsy findings and investigations) and to formulate a comprehensive and data rich report available for researchers undertaking the investigation of still births.

In an attempt to reduce the number of "Unexplained Stillbirths" ancillary investigations are essential. These include always examining the placenta as part of the autopsy, radiology (babygram), microbiology including PCR, cytogenetics and molecular genetics. All of these areas require sufficient funding to be appropriately performed and access to pathologists and pathology services with

expertise in all these disciplines.

The initial stumbling block in obtaining an autopsy on a stillbirth is at the hospital where the death has occurred. To help overcome the often general lack of knowledge about the benefits of an autopsy, local stillbirth support persons should be available to explain and guide the grieving parents through discussions about the autopsy and the benefits, as well as the consent process. These people would be of enormous help in increasing the number of autopsies performed.

The other difficult area currently is the investigation of potential “contributing factors” which if recognised and appropriately addressed may have resulted in a livebirth. This requires information from the hospital where the death occurred and where the mother attended antenatal clinic. This information is difficult to obtain in a centralised service without local co-ordinators at the Hospital where the death occurred. Currently, while some information may be collected locally, it is generally not communicated and while in a single hospital where a death occurred the event may not appear significant, if it is communicated centrally and compared with finding from multiple hospitals, a pattern may emerge that can be addressed.

b) coordination between Australian and international researchers;

This does occur with different research groups in State jurisdictions and via the Perinatal Society of Australia and New Zealand as well as the NHMRC Centre of Research Excellence in Stillbirth (Mater Hospital Brisbane), Australian College of Midwives, Women’s Healthcare Australasia, Sands Australia and the International Stillbirth Alliance. However funding and support for more extensive co-operative research groups is required. Involvement in this process – particularly for the perinatal pathologist - is unfortunately largely on a volunteer and unfunded basis in many jurisdictions.

c) partnerships with the corporate sector, including use of innovative new technology;

It is currently often necessary to send autopsy DNA to international private laboratories for genomic analysis on an ad hoc basis as there appears to be insufficient funding for the public laboratories to develop or set up the panels necessary for the appropriate testing for these often uncommon or rare conditions.

d) sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support;

Currently most research and investigation into Stillbirth cause and prevention is undertaken on a voluntary basis with, if anything, a shoestring budget from Health Departments or Government. There is no funding for stillbirth autopsy under the Medical Benefits Schedule so funding must come from State Health Departments or individual hospitals or patients themselves. It is often difficult for the Paediatric/Perinatal Pathologist to have time allocated or rostered to report autopsies as surgical biopsies from live patients are prioritised by pathology departments. Appropriate funding for all autopsies including perinatal and still birth autopsies is vital to ensure that recognition and acknowledgement of their importance in the Departmental workload is achieved.

- e) research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education;

Determining a cause for every perinatal death is a major priority for all medical staff and parents. It is the vital first step in the investigation and subsequent prevention of stillbirths.

This requires a well organised and co-ordinated organisation including the following:

- Specialist perinatal pathologists +/- training registrars/fellows
 - Dedicated mortuary space and skilled staff
 - Adequate secretarial support and communications
 - Access to interviewing officer/ support person/liaison officer to assist patients and staff in the consent process
 - Adequate viewing room or chapel/pastoral care services
 - Proper and funded arrangements for transportation
 - Access to radiology and photography for all cases
 - Access to cytogenetics, clinical genetics, microbiology and other ancillary departments
 - Ultra-low-temperature freezer for storage of samples including DNA
 - Access to specialist textbooks and journals, databases and websites
 - Funding/support for participation in external quality assurance
 - Funding/support for participation in research and development.
 - Funding for research/administrative staff for the collection and collation of epidemiology and clinical data for correlation with the autopsy findings and cause of death.
- f) communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;

The presence of a trained liaison/support person at all hospitals where there is likely to be a still birth is vital in the communication with families. This is of particular importance for indigenous and migrant families where the issues need to be addressed in an appropriately culturally sensitive manner.

If you have any further questions or comments please do not hesitate to contact Dr Debra Graves CEO RCPA

Yours sincerely

Dr Bronwen Ross
Deputy Chief Executive Officer