

THE FUTURE OF  
PAEDIATRIC PATHOLOGY SERVICES

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# Fetal, Perinatal and Paediatric Pathology: A Critical Future

Report of a Working Group  
to  
restore and develop specialist Paediatric Pathology<sup>1</sup>:  
a critically important specialty,  
essential for the best quality care of children.

The group was convened by

Royal College of Obstetricians and Gynaecologists (RCOG)  
Royal College of Paediatrics and Child Health (RCPCH)  
Royal College of Pathologists (RCPath)  
The British Association of Paediatric Surgeons (BAPS)  
The British Association of Perinatal Medicine (BAPM)

It was important to include informed parent representation, and so two members of the National Committee Relating to Organ Retention and one from the Foundation for the Study of Infant Deaths were invited to participate. A parent, who had been involved personally with organ retention at Liverpool, was also approached. All courageously agreed to be co-opted to the committee. Each committee member, medical or lay, was there both as an individual and a representative of their organisation.

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<sup>1</sup> For ease of reading in this paper we use the term Paediatric Pathology and Paediatric Pathologist. We see this specialty and person covering the areas of Fetal Pathology, Perinatal Pathology, Infant Pathology and Paediatric Surgical and Paediatric Oncological Pathology.

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This paper aims to:-

1. Raise awareness of the importance of specialist Paediatric Pathology for parents and children.
2. Propose practical solutions for the government and the profession to implement in order to recreate a first-class service.

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<sup>2</sup> FSID: Foundation for the Study of Infant Deaths. FSID was founded in 1971 by parents, healthcare professionals and scientists to promote research into the causes and prevention of sudden unexpected infant deaths, to support bereaved parents and to disseminate information to health professionals and the public about infant death and infant health.

<sup>3</sup> CESDI: Confidential Enquiry into Stillbirths and Deaths in Infancy. CESDI is managed by the Maternal and Child Health Research Consortium, which now comes under the remit of the National Institute for Clinical Excellence (NICE).

<sup>4</sup> NACOR: National Committee relating to Organ Retention

## **Foreword**

Paediatric pathologists perform two essential functions. They review and report on biopsy and tissue specimens from children with cancer and a range of other disorders and they carry out post mortem examinations, so that whenever possible parents can be given precise information as to why their child died.

This has always been a shortage specialty and the recent public criticism of pathologists, arising from the issue of organ retention, has made recruitment even more difficult. In June 2001 we invited Professor Neil McIntosh, Professor of Child Life and Health at Edinburgh, to convene and chair a working party to consider how the specialty could be revitalised, so that these essential services for parents and children could be maintained.

This report is the product of much debate by the working group, which included both professionals and parent representatives. It acknowledges the need to change past custom and practice, and sets out proposals for the future. We hope that paediatric pathology can now move forward in a spirit of genuine collaboration with parents and children, to provide the quality of service that we and they would expect.

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4<sup>th</sup> March 2002

## CONTENTS

Executive Summary . . . . .	7
1. Introduction . . . . .	8
2. Purpose of the working group . . . . .	8
3. The scope of paediatric pathology . . . . .	8
3.1. Clinical Services . . . . .	8
3.2. Teaching . . . . .	8
3.3. Research . . . . .	8
3.4. Audit . . . . .	9
3.5. Standard Setting . . . . .	9
4. The role of paediatric pathology . . . . .	9
4.1. Surgical Pathology . . . . .	9
4.2. Tumour Pathology . . . . .	9
4.3. The hospital PM . . . . .	9
4.4. The coroner's PM . . . . .	10
4.5. Research . . . . .	10
5. Manpower and the configuration of Paediatric Pathology . . . . .	10
6. Factors contributing to the shortage of Paediatric Pathologists . . . . .	11
7. Justification for paediatric pathology . . . . .	12
8. The application of paediatric pathology . . . . .	12
8.1. Fetal Medicine . . . . .	12
8.2. Obstetrics . . . . .	13
8.3. Neonatal Paediatrics . . . . .	14
8.4. General Paediatrics . . . . .	14
8.5. Paediatric Surgery . . . . .	14
8.6. Paediatric Oncology . . . . .	15
8.7. Audit of unexpected deaths . . . . .	16
8.8. Child protection . . . . .	16
9. Conclusions . . . . .	17
10. Recommendations of Working Group for action . . . . .	18
10.1. By Government . . . . .	18
10.2. By RCPATH . . . . .	18
10.3. By The other Royal Colleges and Associations . . . . .	18
10.4. By individual Trusts and Health Care Teams . . . . .	19
10.5. By Paediatric Pathologists . . . . .	19
10.6. By Parent groups . . . . .	19

Appendix 1:	
Why is Paediatric Pathology special? . . . . .	20
Appendix 2:	
Post Mortem Examination: considerations for best practice in the future .	21
References . . . . .	26

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## Executive Summary

For many reasons, **Paediatric Pathology is in Crisis.**

The expertise of paediatric pathology embraces two areas:

1. Specialist organ and system pathology, notably surgical and oncological.
2. Post mortem examination<sup>5</sup> of the fetus, newborn, infant, and child.

The unanimous opinions of the **Working Group** are:

1. Pathology and histopathology services for children should be provided in the long term only by paediatric pathologists and those with relevant specialist expertise<sup>6</sup>. This is a matter of training, experience and governance.
2. Paediatric pathology should be concentrated at selected specialist paediatric surgical/ oncological and tertiary referral maternity sites. It should cover all post mortem examinations (inclusive of hospital and coroner's<sup>7</sup>), and all surgical and oncological work, and other work related to fetuses, infants and children.
3. Paediatric pathology cannot be subsumed by general or other specialist pathologists without a further major reduction in both service and quality.
4. The action necessary to enable paediatric pathology to survive the present crisis and flourish requires recognition of its special nature by Government, Health Service Commissioners, the Medical Royal Colleges, and the Specialist Associations.

**Parent groups, clinicians and pathologists are all committed to working together to develop a first-class paediatric pathology service built on mutual understanding and ethical principles<sup>8</sup>.**

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<sup>5</sup> The term post mortem examination will be used for autopsy throughout this document.

<sup>6</sup> Paediatric pathologists have much more expertise in fetal, neonatal, infant and paediatric pathology than other pathologists. On the same principle that heart surgery should not be performed by general surgeons, pathological investigation of the fetus and the child should be carried out by specialist paediatric pathologists.

<sup>7</sup> Coroners' post mortems should be performed by a paediatric pathologist unless there are suspicious circumstances sufficient to involve in addition a forensic pathologist (This is current practice in Scotland, but not England and Wales)

<sup>8</sup> Pathologists with lay input have established new ethical standards (e.g. the Royal College of Pathologists guidelines for the retention of tissues and organs at post-mortem examination, March 2000)

## 1. Introduction

Paediatric pathologists are pathologists who confine their work to the fetus, infant and child. For more than a decade there has been an inadequate number of paediatric pathologists to fill the posts available. The additional pressures resulting from recent events relating to organ retention have compounded this shortage. All members of the working group acknowledged that medical practice in the past had become inappropriate and that the retention of organs without proper authorisation was completely unacceptable. New ethical standards must be established to counter the distrust that past practice has generated. Our aim must be to develop best practice for all areas of paediatric pathology with full openness of information for the patients and parents involved. The public outcry offers an opportunity to change things in favour of a better paediatric pathology service in the NHS with a new contract between the public and profession.

## 2. Purpose of this Working Group

The purpose of this working group was to review the role of paediatric pathology in the context of maternity and child health services and to make recommendations about the future of this speciality and the paediatric pathologist.

## 3. The Scope of Paediatric Pathology

The scope of paediatric pathology is defined by the age of the patient and not by the disease or organ affected. This distinguishes paediatric from adult pathology.

The Speciality of Paediatric Pathology involves:

### 3.1. Clinical Services<sup>9</sup>

- Specialist paediatric surgical pathology, which includes biopsies and diagnostic oncological histopathology
- Fetal, perinatal and infant pathology, which primarily involve post mortem examination and examination of the placenta. The information provided about the baby who has died often also provides information of great importance for parents' decision making and for medical care in future pregnancy or of subsequent children<sup>10</sup>.
- Post mortem examinations in older children may also explain the cause of death and may thus have further implications for the family.

### 3.2. Teaching

Primarily at postgraduate level. Regional centres should provide training in paediatric pathology for all specialist registrars in their region.

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<sup>9</sup> The Bristol Royal Infirmary Inquiry (Kennedy 2001) recommends "[no. 13]. .. children .... must be cared for .... by staff trained in caring for children and in facilities appropriate for their needs" and "[no. 58]..all healthcare staff who treat children must have training in caring for children". It would be illogical to apply these criteria to the living child and then give a second-class service if they require pathological investigation during life, or if they die. The Kennedy report further recommends "[no. 181]..Specialist services for children should be organized so as to provide the best available staff and facilities, thus providing the best possible opportunity for good outcomes." This could particularly apply to surgical and oncological pathology and "[no. 184]..children should always be cared for in a paediatric environment and always by healthcare professionals holding a recognized qualification in caring for children".

<sup>10</sup> With current staffing and support, service is only just maintained. With further decline in staff numbers or support, only a basic service will be possible. (There is evidence on going to press that in London some paediatric pathologists are now having to turn away post mortem examinations.)



### 3.3. Research

Often in collaboration with other specialties, for example, fetal medicine, obstetrics, neonatology and paediatric oncology and surgery. Such research linking clinical disease with pathological findings has been critical for medical advances. It has demonstrably reduced perinatal and infant mortality.

### 3.4. Audit

Audit of clinical services provides invaluable feedback to clinicians about the quality and efficacy of their services.

### 3.5. Standard Setting

A regional centre should set standards (for example by providing protocols) within the region and act as a referral centre.

## 4. The Role of Paediatric Pathology

### 4.1. Surgical Pathology

Histopathological examination of biopsies or tissues and organs removed at operation is essential for accurate diagnosis. Selection of the best treatment often depends on the histological findings, as with Hirschsprung's Disease (one cause of neonatal bowel obstruction). It is also important for surgical audit, for example, to confirm the diagnosis of acute appendicitis, and for training.

### 4.2. Tumour Pathology

Tumour histopathology is vital for the clinical management of patients with malignant disease. The choice of cancer treatment depends not only on an accurate diagnosis but also on predicting how the malignant tumour is likely to behave and how far it has already spread. The paediatric pathologist can provide much of this information and is a vital member of the oncology team. This is fundamental to the success of the UK Children's Cancer Study Group<sup>11</sup>.

### 4.3. The Hospital Post Mortem

The hospital post mortem examination is chiefly to provide information for parents and parental consent is necessary. In the fetus, newborn, infant or child, post mortem examination is not only to find the cause of death (as in the adult) but also to provide information for the parents and their doctors about the implications of that death for a future pregnancy or child within the family. The post mortem examination will also provide a range of useful information for clinicians, helping them to understand the causes and effects of diseases as well as the effectiveness and complications of treatment. It is an important part of audit. **Even if a post mortem examination is not legally required, information from a high quality hospital post mortem examination is the right of every parent following the death of their child.**

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<sup>11</sup> The UK Children's Cancer Study Group (UKCCSG) is a collaborative multiprofessional group, formed in 1977. It operates through 21 regional centres caring for more than 85% of all children with cancer in the United Kingdom. Paediatric Pathologists and those with special expertise in other areas e.g. tumour pathology, neuropathology and bone pathology, have been an essential component of its activities since the outset. They provide central review of diagnosis for all patients entered into clinical trials and often work a network of skilled second opinions in addition to their own local diagnostic work.

#### 4.4. The Coroner's Post Mortem

The coroner's<sup>12</sup> post mortem examination (Procurator Fiscal's post mortem examination in Scotland) is required by law where there is reasonable cause to suspect that the death has been violent or unnatural, or where the death is sudden and the cause unknown. In these situations there may be issues of public interest. The post mortem examination provides information about the medical cause of death. It is important for parents and may allow prevention of similar deaths in surviving or future children in affected families.

#### 4.5. Research

Without research medicine will fail to progress. The paediatric pathologist, working with clinical colleagues, is enabled to conduct far more extensive investigation of illness or disease than is possible during life. This plays a crucial role in advancing fetal and paediatric medicine.

### 5. Manpower and Configuration of Paediatric Pathology<sup>13</sup>

5.1. There are 26 Pathology departments in the UK that have provided specialist paediatric pathology.

5.2. 42 consultant paediatric pathologists are in post in 23 departments. 7 are single-handed. 10 of these posts are part time, including 7 university appointments<sup>14</sup>.

5.3. Currently there are 10 vacant consultant posts (11% of the total) and 2 other consultant posts have been lost. Several posts recently advertised were unfilled. The situation will be aggravated by the retirement of one consultant within the next year and a further 4 within the next 5 years. Many consultants are planning early retirement.

5.4. There are 9 funded specialist training posts in paediatric pathology<sup>15</sup>, of which only 5 are filled. These four trainees are due to complete their training in 2002 - 2005. During the past decade at least four training posts in paediatric pathology have been withdrawn. It is self evident that the current number of trainees is insufficient to meet existing and future requirements.

5.5. There may be scope for some rationalisation of services in some regions, but the present configuration of specialist services has evolved in response to clinical need.

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<sup>12</sup> The coroner's legal role - When the cause of death is due to violence, is unnatural or is sudden of unknown cause, the death must be referred to the coroner. He may direct that a post mortem examination be made, and on the basis of this he may then dispense with the need for an inquest - he being satisfied on the basis of that examination, that the death was not due to violence, nor was unnatural. The coroner must inform those relatives who have asked to be informed of the date, time and place of the post mortem so that any medically qualified representative may attend. In order to avoid losing potential evidence the examination must take place as soon as practically possible. The pathologist is required to preserve material which bears upon the cause of death for such period as the coroner thinks fit (but has to prejudge what might be important, which may only become clear at a later date).

<sup>13</sup> Based on a Census, March 2002.

<sup>14</sup> 11 departments have 2 consultants. 2 departments have 3 consultants, 1 has 4, of whom one is a subspecialist (paediatric neuropathology).

<sup>15</sup> Birmingham (2), Bristol, Edinburgh, Liverpool, Manchester, Sheffield, Hammersmith, Southampton.

## 6. Factors contributing to the shortage of Paediatric Pathologists

Paediatric pathology is an exciting young specialty offering excellent opportunities to develop specialised diagnostic skills and to carry out clinical and laboratory based research. It offers exceptional scope for working closely with clinical teams. Contact with parents is a growing and particularly rewarding aspect of the job for those who enjoy clinical involvement. Diagnostic paediatric pathology has benefited more than any other branch of histopathology from advances in clinical and molecular genetics, making it a rapidly developing and exciting field for young pathologists. Career opportunities are excellent.

The cause of the present shortage of paediatric pathologists is multifactorial. Some factors relate to the working conditions of paediatric pathologists in post, some to an ongoing recruitment problem, and some to both.

- 6.1. There has never been any strategic planning.
- 6.2. Conditions for many consultants are poor. They are often working single-handed with insufficient support staff and no specified budget.
- 6.3. There is an urgency to paediatric pathology. Because of the emotional issues surrounding serious childhood illness and death for the parents, the pressures on paediatric pathologists to provide helpful answers quickly are perceived to be greater than for general pathologists.
- 6.4. Much of paediatric pathology relates to autopsy of the fetus and infant. Post mortem examination is not as enticing as surgical pathology. Examination of babies is emotionally demanding for pathologists in training, particularly if they have a young family of their own.
- 6.5. Recent recognition of the importance of a specialist paediatric post mortem in unexpected infant death has increased referral of these complex cases by Coroners to specialist departments. All require careful discussion with other healthcare professionals, and most deaths prove to be natural. Some are examined jointly with forensic pathologists and involve liaison with the police and a few involve attendance at family or criminal courts. These latter cases, even if few in number, are exceptionally time consuming, significantly increasing the workload of paediatric pathologists.
- 6.6. Managers (and colleagues if a paediatric pathologist works in a general pathology department) may look at numbers of cases but not the complexity of the work, and make incorrect inferences about the contribution being made.
- 6.7. Existing manpower problems have been further exacerbated by recent publicity over organ retention in the Bristol Royal Infirmary Inquiry (Kennedy 2001) and the Royal Liverpool Childrens Inquiry (Redfern 2000). There has been low morale as a result.
- 6.8. Particularly related to recruitment,
  - There is limited exposure to perinatal and paediatric pathology during general histopathological training, implying that the subject is unimportant
  - To be a paediatric pathologist requires additional time in training.
  - The lack of role models caused by poor working conditions and the absence of a properly constituted service are disincentives to recruitment.
  - Remuneration is poor compared to general histopathology.

## 7. Justification for Paediatric Pathology (See Appendix 1)

Could general (adult) pathologists provide perinatal and paediatric pathology services?

Although there is overlap between many aspects of the services provided by general and paediatric pathologists, the practice of paediatric pathology requires a distinctive and individual approach that is different from that applied in adult pathology for the following reasons:

- 7.1 The spectrum of disease in the fetus, placenta and child is quite different from that in adults: in particular in relation to inherited and congenital disorders, and malignant tumours.
- 7.2 Understanding abnormalities in children requires a detailed knowledge of normal developmental changes and processes. Serious misinterpretation may arise without this knowledge.
- 7.3 The preparation of samples from a fetus or child requires a more labour intensive, individual approach.
- 7.4 Samples from children would represent only a small proportion of the workload of a general pathologist, for whom the need for specialist paediatric techniques and knowledge might not be a priority.
- 7.5 Almost all mothers with complicated pregnancies and children with complex or serious disorders are referred to a tertiary obstetric or paediatric centre where access to an on-site dedicated paediatric pathology service is essential.
- 7.6 The distinctness of Paediatric Pathology is illustrated by dedicated textbooks covering paediatric surgical pathology, fetal and perinatal pathology, placental pathology, and paediatric forensic pathology. There are dedicated journals, and specialised national and international meetings and courses.
- 7.7 Paediatric pathologists have their own specialist examination for Membership of the Royal College of Pathologists. They run their own accredited external quality assurance (EQA) scheme whereby they are "tested" on a set of microscope slides twice yearly.

In conclusion, the need for dedicated paediatric pathology is dictated more by the requirements of the clinical service than by absolute population numbers. Paediatric histopathologists must deal with a different range of tissue disorders than general pathologists and their spectrum of knowledge must therefore be different.

## 8. The Application of Paediatric Pathology

### 8.1. Fetal Medicine<sup>16</sup>

**8.1.1** Specialists in this field are expert in the prenatal diagnosis and management of fetal abnormalities using techniques such as ultrasound and invasive procedures. Management of care may involve intrauterine therapy, advice on the timing and mode of delivery or, in some cases, an offer of termination of pregnancy. Unexplained fetal death *in utero* now

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<sup>16</sup> See also *Fetal and Perinatal Pathology* Report of a joint working party of the Royal College of Obstetricians and Gynaecologists and the Royal College of Pathologists. January 2001.

accounts for more deaths than SIDS or preterm labour<sup>17</sup> (CESDI, 1997; Cotzias et al, 1999). Because the methods for examining and investigating the fetus before birth are limited, autopsy of the fetus (or stillborn infant – see below) is more likely to yield important diagnostic information than autopsy after deaths in later life<sup>18</sup>.

**8.1.2.** Examination of the expelled fetus by an expert fetal pathologist provides:

- Information for the parents that may be crucial for future reproductive choices and achieving a subsequent successful pregnancy. Additional anomalies not recognised antenatally are found in up to 40% of cases and the pathologist's description of dysmorphology together with the geneticist's expert knowledge of genetics will directly contribute to determining recurrence risks.
- Confirmation of fetal anomalies after termination of pregnancy. This is important:
  - for audit of screening and diagnostic programmes. This is particularly important with the increasing use of first trimester diagnosis (Shen-Schwarz et al, 1989; Weston et al, 1993 Brand et al, 1994; Isaksen et al, 1999 and 2000).
  - for follow up consultation where it may provide parental reassurance and may help parents come to terms with their loss.
- Feedback which is important to facilitate the development of improved methods for diagnosing abnormalities and evaluating treatments.

**8.1.3.** Close communication with the pathologist, including regular pathology conferences is vital for treatment, teaching, training, audit, and research.

## 8.2. Obstetrics<sup>16</sup>

Complicated pregnancies are managed by obstetricians trained in materno-fetal medicine, often assisted by physicians trained in obstetric medicine.

**8.2.1.** Examination of a stillborn baby or baby who has died in the first week of life by an expert paediatric pathologist is important when death follows pre-eclampsia, growth restriction or preterm labour.

- Perinatal autopsy helps establish not only the cause of stillbirth, but also the timing of death.
- CESDI and other data indicate that a well conducted post mortem examination may identify a cause in 10-30% of cases of otherwise unexplained stillbirths (CESDI, 1999; Incerpi et al, 1997)
- Demonstration of brain injury predating birth or intrauterine death provides important retrospective insights into antenatal management, both for the parents and clinicians. It also has significant implications for risk management. (Volpe, 1995; Becher et al, 2002; Bell et al 2002 – both submitted).

**8.2.2.** Up to 10% of pregnancies, where the baby survives, will have a complication warranting pathological examination of the placenta (Taskforce of the College of American Pathologists, 1997). This may provide clues about the presence of underlying thrombophilias, congenital infection, the aetiology of preterm labour or premature rupture of the membranes,

<sup>17</sup> In 1999, there were 2521 unexplained antepartem fetal deaths, 372 SIDS, 78 unascertained deaths and 1348 deaths from prematurity in England and Wales.

<sup>18</sup> The Paediatric Pathologist may be the first and last doctor to examine a baby, and so their examination must be expert, thorough and particularly well documented.

impaired trophoblast invasion in maternal pre-eclampsia and fetal growth restriction, the cause of maternal bleeding, and the vascular complications of monochorionic twins.

### 8.3. Neonatal Paediatrics

**8.3.1.** Neonatologists care for small, immature and often sick infants, some of whom do not survive. A post mortem examination performed by a perinatal pathologist will usually involve both the newborn infant and the placenta. It will provide feedback:

- To the bereaved parents, with information that may be important in understanding why their baby died and for making future plans.
- To the neonatologist, enabling the effectiveness and appropriateness of treatment to be audited and further developed.
- To the obstetrician, sometimes establishing the aetiology of preterm labour, but always giving information about the infant and placenta that will be needed when managing future pregnancies.

**8.3.2.** In addition biopsy from newborn infants with e.g. the bullous dermatoses, hepatitis, bowel obstruction, chronic lung disease or congenital cystic adenomatoid malformation of the lung may allow better medical and surgical management of important conditions.

**8.3.3.** In the live newborn infant examination of the placenta and umbilical cord may aid management of infection.

### 8.4. General Paediatrics

**8.4.1.** In the post neonatal age group, unexpected infant deaths are the major cause of mortality accounting for over a third of post neonatal deaths. Such deaths are referred to coroners who need the expertise of the paediatric pathologist to give the medical cause of death and to distinguish between natural and unnatural death. Unexpected infant deaths are due to a wide range of paediatric conditions some of which are very rare e.g. endocrine or metabolic conditions. Rare conditions may only be evident from histology, bacteriology, virology, toxicology and other tests arranged by the paediatric pathologist. Sudden infant death syndrome (SIDS), meaning the cause of death was natural but not determined after a thorough post mortem examination, should only be diagnosed after these tests are completed and specific rare conditions have been excluded and consultation with other professionals involved has taken place.

**8.4.2.** Deaths are not common after infancy but may occur suddenly due to traumatic injury or overwhelming infection such as meningococcal septicaemia, or due to a progressive disease such as malignancy or kidney failure. Specialist knowledge and experience is necessary to ensure that the maximum useful information is obtained about the cause of death and quality of care.

**8.4.3.** The treatment of a number of conditions is greatly helped by knowledge obtained from biopsies. For example, in infants and children with chronic liver disease a liver biopsy may be obtained to enable the progress of the disease to be followed.

### 8.5. Paediatric Surgery

**8.5.1.** Histological examination of tissues removed at operation form the bulk of paediatric surgical pathology. These include biopsies from organs or tumours, as well as excised organs such as the appendix or kidney. Many of the conditions are unique to children. Accurate diagnosis is essential to ensure the best treatment for the patient.

**8.5.2.** Surgical biopsy may greatly assist the diagnosis of metabolic disorders (liver biopsy) and neuromuscular conditions (muscle or nerve biopsy).

**8.5.3.** The need for histopathology may be urgent, such as for an informed opinion on frozen sections from biopsies from the bowel for suspected Hirschsprung's Disease (an uncommon but serious cause of intestinal obstruction in the newborn infant), and from tumours, many of which are uncommon and unique to children.

**8.5.4.** Regular multidisciplinary pathology conferences with the pathologist and specialist surgical and oncological teams are vital for making the right diagnosis, fully understanding the clinical problem, and planning the management of the individual child. These meetings are also important for auditing surgical diagnosis and treatment, for teaching and training surgeons and other clinicians, and for research.

**8.5.5.** In general, deaths are not common in paediatric surgery. Post mortem examinations play an important role in clarifying the cause of death when it does occur, understanding why things sometimes go wrong, and documenting previously undiagnosed anomalies. This is very important following an operation or traumatic injury.

**8.5.6.** Research and development in many areas of paediatric surgery depend on input from the paediatric pathologist, for example, accurately identifying anatomical abnormalities in congenital cardiac disease.

**8.5.7.** Close collaboration between surgeon and paediatric pathologist is fundamental to developing new methods of treatment.

## 8.6. Paediatric Oncology

**8.6.1.** The accuracy of diagnosis and disease classification is fundamental to the effective treatment of malignant tumours, where survival depends on targeting treatment to the specific type, grade and stage of tumour<sup>19</sup>.

**8.6.2.** Many tumours are uncommon and unique to children, and specialist knowledge and experience is required to interpret the tissue samples sent to the laboratory (Parkes et al, 1997).

**8.6.3.** The success of the UK Children's Cancer Study Group<sup>20</sup> in reducing mortality from childhood cancer has been due to the effective collaboration of specialist paediatric surgeons, paediatric oncologists and paediatric pathologists.

**8.6.4.** The contribution of the paediatric pathologist is essential to the design of treatment protocols, planning the appropriate methods of biopsy, defining how the specimen should be handled after removal and ensuring that appropriate cytogenetic and molecular genetic studies are done. The pathologist is also closely involved in monitoring the results of treatment.

<sup>19</sup> For example it is no longer adequate for a pathologist merely to confirm the clinical diagnosis of a neuroblastoma; in order to plan treatment it is now important for the clinician to know about the pathological grading of the tumour, the status of amplification of the MYCN oncogene and the presence or absence of other cytogenetic changes. Similarly when confronted with a child with a bladder sarcoma, the informed pathologist needs to be able to debate the significance of residual but mature tumour cells in a post chemotherapy biopsy before the paediatric oncologist recommends to the paediatric surgeon that radical surgery such as bladder removal is necessary to control disease. These apparently subtle points are critical to the management of an individual child.

<sup>20</sup> UK Children's Cancer Study Group; see footnote 11. A thriving and active paediatric pathology community is needed to provide the review panels that underpin the clinical trials and studies on which continuing progress depends.

## 8.7. Audit of Unexpected Deaths

**8.7.1.** The Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) has clearly demonstrated the essential role of the perinatal/paediatric pathologist. An objective review of 450 sudden unexpected infant deaths demonstrated serious deficiencies when the post mortem examination was carried out by a non-paediatric pathologist, with essential tests being omitted in up to 70% of children. The diagnosis was deemed to be incorrect in an estimated 20% of cases; this led to failure to recognise inherited conditions and on occasions led to inappropriate suspicion of harm. Based on this review, paediatric pathologists have developed an evidence-based protocol for the examination of unexpected deaths.

### 8.7.2. Sudden unexpected death in infancy.

- Where a baby dies suddenly and for no obvious reason, parents are left with the all consuming question “why?” and feelings of guilt, even though they know they are blameless. A carefully performed post mortem examination is crucial to seek a diagnosis, and paediatric pathologists are best able to provide this because of their knowledge of infant disease.
- There are a number of medical and forensic problems with the present system for investigating sudden infant deaths, including great variability in different parts of the country. FSID launched a campaign in 2000, called “Responding when a baby dies”, to improve and standardise the approach. The recommendations include:
  - A paediatrician and a specially trained police officer should visit the bereaved family at home within 24 hours of the baby's death to take a full history of the preceding events
  - A thorough post mortem examination of the baby should be carried out by a paediatric pathologist who has access to the information gathered in the home interview
  - A case conference should be held among all the professionals involved with the baby, including the pathologist, to learn as much as possible about the factors contributing to the death and draw lessons for the future
  - All of the above should come under the authority of the coroner
- The Foundation for the Study of Infant Deaths (a charity involving parents of infants who have died suddenly and unexpectedly) has produced new guidelines for the many professionals involved in investigating cot deaths. Paediatric pathology plays a key role in the campaign to research and eliminate SIDS – without adequate pathology there can be no success.

### 8.7.3. Surgical Audit

The National Confidential Enquiry into Perioperative Deaths (NCEPOD - [www.ncepod.org.uk](http://www.ncepod.org.uk)) carries out selective independent review of deaths in England and Wales. In Scotland, a more recent and comprehensive system audits all childhood (and adult) deaths where a surgeon has been involved whether or not the child has had surgery (The Scottish Audit of Surgical Mortality - [www.show.scot.nhs.uk/sasm](http://www.show.scot.nhs.uk/sasm)).

## 8.8. Child Protection

**8.8.1** When the underlying cause of death of babies or children may be unnatural, such as smothering or Fabricated or Induced Illness (formerly called Munchausen Syndrome by Proxy) a detailed knowledge of possible suggestive histories, the potential pathology and how the post mortem should be conducted is critical. Accumulation of evidence in a cor-



rect manner may lead to the successful identification and prosecution of the perpetrator but, more importantly, it may lead to measures designed to protect other children or babies. Equally important, expert pathology may prove someone's innocence by demonstrating natural disease.

**8.8.2** Paediatric pathologists conduct some examinations alone but many are conducted jointly with forensic pathologists<sup>21</sup>. Experience in liaising with the police, producing reports for the court and presenting evidence in court is a facet of the paediatric pathologist's work which is of critical importance to the legal system and barristers now understand that they need the knowledge and experience of the Paediatric Pathologist for substantiation of diagnoses.

**8.8.3** Following the murders by Beverley Allitt, the Clothier report recommended a review of services such that a Paediatric Pathologist should be engaged in all unexpected infant and child deaths whether in hospital or the community<sup>22</sup>.

## 9. Conclusions

**Paediatric pathology is in crisis. IT REQUIRES AN URGENT STRATEGIC REVIEW.**

- 9.1.** Paediatric pathology is a vital component of a comprehensive health service for parents and children. Parents and children are a government priority throughout the UK, thus paediatric pathology should be part of the National Service Framework agreement.
- 9.2.** The professional representation of the Working Group indicates the widespread concern about the current provision of paediatric pathology. The Medical Royal Colleges and Specialist Associations feel that the present situation severely prejudices the current and future service for fetuses, newborns, infants and children.
- 9.3.** The lay members of the Working Group all independently recognised that failure to address the problems of paediatric pathology would lead to an immediate and further shrinkage in services with subsequent adverse effect on progress in the fields of fetal, and perinatal medicine and child health.
- 9.4.** Paediatric Pathologists should be based at selected lead tertiary specialist centres. An appropriate skill mix is required at these centres<sup>23</sup> to provide for local and regional service demands, as well as teaching and research.
- 9.5.** The current manpower shortage needs to be addressed urgently by the Government, the Medical Royal Colleges and the Specialist Associations. This includes:
  - Recognition of the workload of paediatric pathologists.
  - Support for present medical, technical and secretarial and clerical staff and incentives to encourage them to remain in post.

<sup>21</sup> In Scotland, all single doctor Procurator Fiscal's autopsies on children are conducted by a Paediatric Pathologist. If the Crown Office wishes a criminal review, the autopsy is conducted by a Forensic Pathologist in conjunction with a Paediatric Pathologist. This is not so in England and Wales, though a similar system is practiced in some areas (eg London).

<sup>22</sup> The Clothier Report. The Allitt Inquiry: Independent inquiry relating to deaths and injuries on the Childrens ward at Grantham and Kesteven General Hospital during the period February to April 1991. HMSO Publications.

<sup>23</sup> A minimum of three Paediatric Pathologists is needed at each centre. Some centres will need more to cover a full time service with the increasing specialisation that is required within the subspecialty.

Paediatric pathology has been largely forgotten in all previous planning processes and has struggled with *ad hoc* development and funding. The current circumstances can largely be attributed to uncertainties about the future. There have been no clear guidelines from the Department of Health and in some Trusts managers are proposing to close laboratories, merging paediatric and adult services, without adequate consideration of the consequences.

## **10. Recommendations**

### **10.1. The Government must:**

- Clarify the law relating to organ retention to protect parents, relatives, future children and professionals (see Appendix 2). The working group accepts the recommendations of the Chief Medical Officer and are supportive of the work of the Retained Organs Commission.
- Ensure strategic planning for paediatric pathology through the Strategic Health Authorities and via the National Service Frameworks for Maternity and Child Health
- Create and adequately resource recognised centres to provide this service.
- Paediatric pathologists should be based at selected lead tertiary specialist obstetric and paediatric centres where a full range of obstetric and paediatric services are provided, notably fetal medicine, paediatric oncology and paediatric surgery and intensive perinatal care.
- Ensure resources include an appropriate working environment and adequate support staff, both technical and secretarial
- Provide incentives to Deaneries and to Trusts to attract and retain trainees in the specialty
- Reassure and inform the public that this is an essential service that is practised by NHS doctors as committed to patients and their families as anyone else in the linked specialist fields of obstetrics or paediatrics
- Clarify the law relating to organ retention to protect parents, relatives, future children and professionals (see Appendix 2)
- Develop a **workable** national consent form
- Ensure funding for and encourage research in the specialty.

### **10.2. The Royal College of Pathologists must:**

- Employ strategies to make paediatric pathology attractive for trainee pathologists. (see section 6)
- Recommend standards for training and service in specialist centres
- Appoint a National College Adviser to supervise paediatric pathology trainees
- Formally recognise and emphasise to the Specialist Training Authority the status and importance of the specialty. This might include recognition of paediatric pathology as a distinct subspecialty
- Increase the exposure to the specialty during training in histopathology
- With Postgraduate Deans, allocate dedicated training numbers for paediatric pathology
- Consider the promotion of paediatric pathology amongst paediatric and obstetric trainees as a worthy career choice
- Separately assess (by Clinical Pathology Accreditation [UK]) the workloads of paediatric pathologists and adult pathologists in large departments.

### **10.3 The Royal Colleges of Obstetricians and Gynaecologists and Paediatrics and Child Health and the British Associations of Paediatric Surgeons and Perinatal Medicine must:**

- Press for recognition of Paediatric Pathology as a priority area. As a critical support

speciality it must be encouraged to flourish.

- Reinforce the sense of value they have for Paediatric Pathologists.
- Demand a high quality and appropriately resourced regional service
- Ensure when accrediting their own specialist training that specialist Paediatric Pathology back up services are present e.g. Accreditation for Fetal Medicine would be inappropriate in the absence of a strong paediatric pathology service.

#### **10.4. Individual Trusts and Health Care Teams must:**

- Ensure they are part of a network providing specialist perinatal and paediatric pathology
- Ensure a high quality paediatric post mortem is offered as a right to every parent who has lost a child before or following birth
- Ensure every clinician receives training in communicating issues about post mortem examination sensitively and frankly to parents, including sensitivities about relevant ethnic and religious issues.
- Be prepared to seek consent for research as part of the authorisation of post mortem examination
- Audit its autopsy rates and account for these to the Confidential Enquiries
- Ensure appropriate and timely arrangements are in place for results and their implications to be communicated back to the parents

#### **10.5 Paediatric Pathologists must:**

- Take every opportunity to explain and promote paediatric pathology and paediatric post mortem examinations to other professionals, parents and the general public
- Be available to parents, assist clinicians in the consent process, and explain post-mortem findings to parents whenever requested to do so
- Promote their specialty as a career choice to medical students, junior pathologists and trainees in other specialties
- Continue to press the case for necessary local service developments supported by carefully reasoned and costed plans
- Continue to work with parent and professional groups to develop and implement codes and standards of practice in paediatric pathology
- Not acquiesce to sub standard facilities, resources or support services but act as advocates on behalf of and with parents to achieve a uniformly high standard of service nationally

#### **10.6 Parent Groups**

Parent groups (MACOR, SANDS<sup>24</sup>, FSID, NACCPO<sup>25</sup> etc) must work closely with the professional groups to establish standards, ensure good practice and communicate with the general public (see Appendix 2)

**PARENTS, CLINICIANS AND PATHOLOGISTS ARE ALL COMMITTED TO DEVELOPING PAEDIATRIC PATHOLOGY FOR THE OPTIMAL BENEFIT OF PARENTS AND CHILDREN.**

<sup>24</sup> Stillbirth and Neonatal Death Society

<sup>25</sup> National Alliance of Childhood Cancer Parents Organisations

## Appendix 1 - Why is Paediatric Pathology special?

### Paediatric Surgical Pathology:

1. Necessitates a **specialist body of knowledge** reflected in textbooks of paediatric surgical pathology and paediatric tumours. Children's diseases are often rare and not organ based – e.g. metabolic disorders, syndromes (eg tuberous sclerosis). Even if organ based, the conditions are very age dependent (eg biliary atresia). Many children's tumours are specific to children.
2. Needs **close liaison with appropriate clinicians** (e.g. paediatric surgeons, nephrologists or oncologists) for the diagnostic process and for patient management.
3. Is often carried out in **facilities separate from general histopathology**. Special techniques are frequent with routine use of cytogenetics, electronmicroscopy, molecular studies, and immunohistochemistry with different antibodies from those used in adult pathology (United Kingdom Childrens Cancer Study Group protocols)
4. Is **done better by paediatric pathologists**. In continental Europe, most paediatric tumour biopsies are reported by generalists. Many such diagnoses need correction when reviewed by specialist review panels in comparison to the United Kingdom Childrens Cancer Study Group, where most initial tumour diagnoses are made by paediatric pathologists. (Vujanic et al, 1996 and 2000)
5. Is subject to **regular audit** – e.g. the reviews of histology by the UKCCSG panels and the twice yearly slide test (BRIPPA External Quality Assurance Scheme)

### Fetal, Perinatal and Infant Pathology:

1. Also has its **own body of knowledge** of the congenital and genetic origins of disease. This is reflected in its major specialist textbooks, computer databases (eg of dysmorphology), specialist journals and it's own specialist societies (British Paediatric Pathology Association and the International Perinatal Pathology Association). In the United Kingdom it also has it's own accredited external quality assurance scheme.
2. Has its **own special techniques** (not familiar to general pathologists) and gives an **increasingly regionalised service**. Paediatric pathologists would not attempt to carry out post mortems on adults because of a lack of expertise. Similarly general pathologists have become "de-skilled" in paediatric pathology. It is not surprising that several studies show that perinatal pathologists consistently provide better and more clinically relevant reports (Vujanic et al, 1995; Rushton, 1991).
3. Demands very close **clinical contact** for patient management and maintenance of specialist expertise. Patient (parent) contact in conjunction with obstetric or neonatal colleagues is common and is likely to be more common in the future.
4. Is **essential for clinical audit and governance** – This applies to diagnostic services (eg the fetus), for management of the infant receiving intensive care and for the investigation of the sudden unexpected infant death.
  - Many reports indicate that paediatric pathologists generally achieve greater accuracy in their specialist area. (Fleming et al 2000; Vujanic et al, 1995; Vujanic et al 1996; Thornton and O'Hara, 1998).
5. Is the best protection against misguided obstetric litigation eg. in birth asphyxia (Kraus, 1997; Schindler, 1991).

### Post-mortems in older children

Numerous studies show the value of careful autopsy in different paediatric clinical groups such as cardiac cases (Gatzoulis et al, 1996; Russell and Berry, 1989), paediatric oncology (Koszyca et al, 1993), accident and emergency (Whitehouse et al, 1994) and infectious diseases.

## APPENDIX 2 - Post Mortem Examination – considerations for best practice in the future

### 1. General issues

How the Paediatric Pathologist and clinicians interface with relatives and the general public with respect to consent for a post mortem examination and the retention of tissues and organs has to be considered as a matter of urgency, as it is the public and future generations of children that will lose out if the issues are not addressed. The fact that 20-40% of perinatal autopsies reveal new information is not just a reflection of the limitations of clinical and diagnostic medicine, it is also because of the complex ramifications of disease and abnormality through the human body. Thus it is as important to examine the brain as it is the heart in the “cardiac case” and the lungs and heart as well as the brain in the baby dying of a brain haemorrhage. It is only with openness and public education that these issues can be understood. The Working Group believes that a serious service deficit will result if the post mortem rate significantly declines.

Parents must be free to decide for or against a hospital post mortem examination with the best possible information. Even if the post mortem is legally required by the coroner, parents should be given detailed information. This should include:

- What a post mortem examination (autopsy) is
- Who does it
- What it is for
- Why it is useful in general
- Why it might be particularly important for them
- When and where it will happen and why there.
- Possible reasons for tissue and organ retention – see below

Although all this information should be available on a clear, non-ambiguous Nationally Accepted Information/Consent form used for hospital post mortem examination, someone with experience must have the time and sensitivity to go over this information with the parents, who can then make an informed, unpressured and unpressured decision.

### 2. The hospital post mortem examination (PM)

Each hospital should have an identified, experienced and trained member of staff (clinical or other), who knows what is involved in the post mortem process, and who seeks consent. It is more important that it is done well, than by a particular brand of person. That person can bring in a paediatric pathologist to give detail if appropriate.

The teaching aspect of requesting consent must also be addressed. A member of the junior staff involved in the case and known to the parents should additionally be involved if possible.

The request for a post mortem examination itself must be to a minimum standard. Specific consent is required for all aspects of the examination.

- There needs to be a simple yet complete explanation of what is done and what is involved in a manner which minimises additional distress to parents.
- It should be made clear that autopsies are done for three reasons:
  1. To provide important information to the parents. The pathologist may be able to confirm the cause of death or show other problems not diagnosed in life. Parents should always receive both verbal and written communication about the findings and their implications.
  2. To provide important information for the clinical team. The post mortem may confirm everything, or may show things were missed or that there were complications associated

with the treatment itself. This knowledge should lead to audit of conditions and procedures with consequent better management of future children with similar problems.

3. The small organ blocks used for histological diagnosis are usually archived (kept, potentially for ever). This allows the pathologist to audit and confirm their naked eye observations at PM, to maintain and increase their expertise and to audit their diagnoses made from small biopsies taken in life. It also allows the medical team to revisit the problem when medicine has advanced. New diagnoses of importance to the family can sometimes be made years after the child's death using new genetic tests on retained tissue samples. This material can also be used for public health and epidemiological research at a future date, e.g. variant CJD. Such stored samples should not be used for commercial gain.

If a post mortem examination (hospital or a coroner's examination) is to be done parents want the best possible information from it - this depends on the skill and technical knowledge of the paediatric pathologist and the quality of the communication of the results to the parents. Parents should be told the initial findings and the later results of any special tests as soon as they are available. Feedback of this information should be by the clinician who requested the post mortem examination on behalf of the parents. The clinician could reasonably perform this in conjunction with the pathologist. A copy of the final post mortem report should be offered to them. The implications from the results should be given in writing for their easy future reference.

### **Retention of material at hospital post mortem examination – the future**

Any material retained must be with the full knowledge and consent of the parents. Retained material should not be used for commercial gain.

The types of material that might be important to retain are:

- Body fluids – blood, urine, spinal fluid
- Microscope slides with very thin sections of organs on them
- Small pieces of organs (tissues) – these are frozen or embedded in wax so that microscope slides can be prepared – histology.
- Whole organs e.g. heart, brain, kidneys etc

There are many important reasons for retention of material:

- To obtain the maximum information for the family at the time - eg if the brain is not fixed (hardened) before examination, then much less can be learned from it. This takes 3 to 6 weeks.
- For further diagnosis eg with archived material, further information for the family may be available in the future; this is especially important when the post mortem examination fails to reveal a cause of death

Other reasons for retention include donation, teaching and research:

- Gifted organs obtained at post mortem examination such as the heart, kidney or brain are valuable for teaching students, doctors and other medical professionals.
- Donated tissue such as bone and cardiac valves obtained at the time of post mortem examination can be transplanted to living patients.
- Information from small archived tissue blocks can be used for audit, teaching and research

Most parents support research even at times of extreme stress e.g. in a recent Scottish Study (1996-1998), 65% (88 of 136 sets) of parents whose infants died in the first week of life consented to autopsy. 77 of the 88 parents consented to fixation of the brain and detailed examination for a research study (Bell et al, 2002). This study showed that over half the

infants that had birth asphyxia and died had changes in the brain that could be identified as having occurred before labour. This significant advance in knowledge has been made possible in large part by these consenting parents.

- The working group has to point out that since 1997, the number of papers presented from the UK to the Paediatric Pathology Society (of Europe) has fallen in successive years from 57% of the total in 1997, through 37%, 22%, 9%, to 2% in 2001 reflecting the strains current in this speciality.

When consent is given by parents for retention of material following a hospital post mortem examination the medical profession would prefer it to be for an unspecified and unlimited time as such archived material is potentially extremely important for the advancement of medicine. This was also accepted by 2 of the lay representatives on the committee and other lay groups who proof read the document. The executive of NACOR felt that parents should be offered the option to specify retention only for a specific period with return of the material after this for disposal. Although this would be theoretically possible, even with good information technology it might be organisationally difficult.

## 2. The coroner's post mortem examination

The coroner's post mortem examination (Procurator Fiscal's post mortem examination in Scotland) is required by law where there is reasonable cause to suspect that the death has been violent or unnatural, or where the death, usually within the community, has been sudden and the cause unknown.

When there is a sudden unexpected death in an infant or child the post mortem examination may:

- Show a clear cause of death – natural or unnatural, or
- Fails to show a cause of death.

The term sudden infant death syndrome (SIDS), is used when no cause of death is established but, on the balance of probability, it was natural. This allows registration of the death and such registration should only occur after consultation with other professionals involved in the case, and after a thorough post mortem examination inclusive of many tests (e.g. bacteriology, virology, toxicology and other) that exclude specific rare conditions. Thus registration of death as SIDS indicates a diagnosis was not established.

Later further questions may arise about the cause of such a death – for example if another child dies or nearly dies in the family. This could indicate a rare familial inherited condition or that deliberate harm is occurring within the family. Without retained material it is impossible to investigate these issues.

Retained tissue may enable a rare metabolic or genetic diagnosis to be made for the family years after the death and this may be of great importance for other children, present or future, in that family. Retention of tissue also potentially gives the ability to establish innocence if there is later accusation of harm.

For society, it means that if the question of specific harm is later raised, it may be possible to prove. In this situation it may then be possible to protect other children in the family from similar harm – a principle underpinning the Children Act, that the child's interests are paramount.

Retention of material after a coroner's post mortem examination is not presently sanctioned in law although there is some difference of opinion regarding this matter. Retention of material

as wax embedded blocks and slides from selected cases would be invidious, but the retention of this material as a routine part of the coroners records would remove any stigmatisation on individual families and allow the family or society to address these issues when and if necessary. At present parents have every right to refuse retention, and should not be blamed for a wish to see their child buried complete, or if unavoidably damaged, for example by surgery or accident, at least as complete as possible.

The balance of these issues must be considered by a body with executive powers. The Working Group believe there is some urgency to these considerations, and suggest that either the Retained Organs Commission or Government, possibly in their imminent review of the coroners services, should address this issue.

### 3. Alternatives to current post mortem examination

It is possible that as a result of changing public expectation and a more rigorous consent process that hospital post mortem examination will become less common. Before alternatives to full post-mortem examinations are offered routinely, proper comparison must be made with conventional post mortem. The Working Group made the following points about the present PM:

- Formal post mortem examination requires both careful dissection and the processing of material for microscopic examination.
- It is perhaps surprising that these 2 basic techniques of careful anatomical dissection and simple histopathology (using such stains as haematoxylin and eosin) are as important now as over 100 years ago.
- Proper gross anatomical and histopathological examination of the brain requires its fixation (hardening) in formalin over a period of weeks. Examination without fixation is suboptimal.
- Except for diagnosis of a gross congenital malformation, histopathology is always warranted, and, even then to explain the underlying reason for a malformation both histopathology and molecular biological techniques may be required.
- In addition to the 2 basic techniques, in almost all perinatal autopsies photos are taken of the external appearances and xrays of the skeletal features. In some cases magnetic resonance imaging (MRI) is also performed, but this is to complement the basic post mortem examination not to replace it.
- In addition molecular biology and other genetic techniques may be used in specific cases.

Over the last few years, some have advocated "limited post mortem examination" or "needle biopsy post mortem examination" (which obtain very small tissue fragments), or the use of Magnetic Resonance Imaging (MRI) or "MRI guided biopsy". The Working Group stresses:

- There is little evidence that these are valid alternative to post mortem examination, though specific biopsy might be able to confirm a particular diagnosis made before death, and MRI might reveal some cases of congenital malformation. MRI might even be the choice to examine the brain morphology in a macerated stillborn infant. In contrast, following traumatic head injury, direct examination has been shown to be superior to scanning (Hart et al, 1996).
- Neither specific biopsy nor MRI would be useful in most cases of infection, metabolic problem, or for the diagnosis of suffocation etc, nor for the exclusion of specific causes of death in unexpected infant deaths.
- If limited biopsy or MRI directed biopsy is to be advocated at all, then the working group believes it should only be after careful, prospective research studies.
- Such studies should determine the usefulness of the techniques using post mortem examination as the gold standard against which comparison is made. It is important to



know about:

- Missed diagnoses (false negatives)
- Diagnoses not then confirmed at post mortem examination (false positives),
- Cost evaluations
- Health, safety and patient acceptability (separate scanner for the live and the dead?)

**Conclusion** Conventional post mortem examination remains the gold standard until rigorous studies demonstrate an alternative. Governance dictates that any changes to the current best practice of conventional post mortem examination must be on the basis of evidence which at present does not exist. Paediatric Pathologists, Obstetricians and Paediatricians are committed to developing the paediatric post mortem examination so that the consent process, procedure and information gained meet the needs and expectations of parents and the wider public.

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