UK Cardiac Pathology Network

Dr. Margaret Burke

on behalf of the
UK Cardiac Pathology Network
Steering Group
BDIAP, November 2009
## Diagnostic Histopathology

The continuously updated review of diagnostic histopathology (formerly Current Diagnostic Pathology)

### Mini-Symposium: Non-forensic Autopsy

**Editor:** Ian Roberts

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| A surgeon's guide to pre-operative death | 37 | Angus J W Wilson, Ewan W. Kersen |

| Post-mortem toxicology of community-acquired drugs | 33 | Alexander R. Allen, Iain C. Roberts |

### Review

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### Instructional Cases

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**Affiliated with the Pathological Society**

**Editor-in-Chief**

**Simon D. Cleave**

% Reader and Honorary Consultant at the Academic Unit of Pathology, University of Sheffield, UK.
UK Cardiac Pathology Network
(December 2006)

Aim

To promote best practice in the pathological investigation of cardiovascular disease and sudden death of probable cardiac origin (SCD) in the UK

Potentially inheritable non-ischaemic non-valvular diseases
Why the network?

- Sudden cardiac deaths (SCD) in young people from potentially inheritable heart muscle disease or arrhythmias is commoner than you think!

- Cardiological screening of 1st degree relatives showed inherited cardiac conditions in a significant proportion of cases

- Family support groups have highlighted the problems faced by families affected by SD

- Correct approach at autopsy dependent on ..........
  - working to protocol within the law
  - persuading families to agree to retention of relevant material
  - getting full and accurate history and consents
  - “thinking ahead” before the autopsy and discussing case with cardiac pathologist
Membership

Specialist cardiac referral pathologists

**Adult**
- Mary Sheppard (RBH)
- Sian Hughes (UCL)
- Kim Suvarna (Sheffield)
- Patrick Gallagher (Soton)
- Helen Doran (Manchester)
- Desley Neil (Birmingham)
- Margaret Burke (Middlesex)
- Martin Goddard (Papworth)
- Doris Rassl (Papworth)
- Sebastian Lucas (GKSTMS)
- Joe Boyle (RPMS)
- John McCarthy (Cheltenham)

**Paediatric (<16, excluding SIDS) and Complex CHD**
- Michael Ashworth (GOS)
- Yen Ho (RBH)
NSF Expert Group 2004-05

With many, many others………

- Prof Bill McKenna
- Dr. Perry Elliott
- Dr. Mary Sheppard
- Mr. Michael Burgess HMC
- Dr. Andrew Reid HMC
- Family Support Groups

- Considering the feasibility of guidelines on how these deaths are certified;
Quality Requirement Three – Sudden Cardiac Death

Aim: To reduce mortality from sudden death and improve services for families who have lost a close relative.

Quality requirement: When sudden cardiac death occurs, NHS services have systems in place to identify family members at risk and provide personally tailored, sensitive and expert support, diagnosis, treatment, information and advice to close relatives.

18. A standard post-mortem, which specifically looks for the commonest causes of premature sudden death, has been drawn up by the Royal College of Pathologists. This includes preservation of appropriate tissue if required for subsequent DNA extraction and histological review. Consent from the family must be obtained for any samples to be held for future testing. Appropriate involvement of the coroner, pathologist and family doctor in the management of these cases helps to ensure appropriate case identification.

SCD 5.pdf

The Royal College of Pathologists

Guidelines on Autopsy Practice

Scenario 1: Sudden death with likely cardiac pathology

SCD 6.pdf

Information for Coroners
A laudable aim – some joined-up thinking……..

Retention of appropriate material
Coroner’s Act (1988) and Rules (1984) [currently under review]
From Jan 2006

- Informal Pathology group – Chair: Dr Perry Elliott (Cardiologist, UCHL), 6 pathologists

- “Wish List” to DH
  - Cardiac Pathology Network (CPN) comprising “Expert Group” and wider membership of DGH, teaching hospital and forensic pathologists
  - Cardiac examination done to an agreed national protocol
  - Paediatric Cardiac Pathology (exclude SIDS)
  - National SADS database
  - Links to Arrhythmia Clinic network
  - Funding

- Seek College support to recruit to CPN

- DH Coronial/Pathology Implementation Group
  - 31 members (including Coroners, representative of COA, pathologists)
College meeting, Dec 06

Concerns

Autopsy protocol

The Coroner

Education and training

The database/network
UK CPN Steering Group

- December 2007
- Facilitated by Department of Health
- Terms of Reference
- Membership
  - Co-Chairmen [cardiologist + pathologist]
  - Secretary
  - Cardiac, Paediatric, DGH, Teaching Hospital, Forensic Pathologists
  - Representatives of RCPathologists, Coroner, Coroner’s Officer, NSF Genetics SI Group, MoJ/DoH pathologist
  - Second cardiologist
  - DoH Observers
Membership
(as of Nov 2009)

Total members - 53
DGH +/- University – 31
Forensic – 10
Cardiac – 10
Paediatric/Congenital – 2
At the beginning of the case, THINK AHEAD:

Might I need to refer the heart to a cardiac pathologist?

Should I consult a cardiac pathologist to decide how best to proceed?

(Details of cardiac pathologists on UK CPN website)

Should I conduct the case according to the UK CPN protocol?
Retention of heart – options (depending on expertise)

1. Retain heart for onward referral (referral centre to keep or discard after sampling)

2. Retain heart for onward referral (allow photography and sampling/retention of tissue blocks/return heart for funeral) - but is more sampling necessary?

3. Retain midventricular slice and blocks from RVOT and atria (minimum) for referral

4. Digital photo and mapped sections
Dissection …..
Mapped blocks
Also remember!

- Clinical and family history
- Digital photography of specimen
- Fresh tissue – spleen (DNA), blood (toxicology, mast cell tryptase)
- Consent for long term storage of histological and fresh material
- Information about SADS database (if appropriate)
- Report – diagnosis, recommend referral of family for cardiological screening
- Information about family support groups
Education and training

- **Courses/secondments**
  - Biennial meetings of Association for European Cardiovascular Pathology [http://anpat.unipd.it/aecvp/](http://anpat.unipd.it/aecvp/) also affiliated to ESP
  - Annual UK CPN meetings
  - CMA-sponsored days in 2007 and 2008

- **National & international training initiatives**
  - European and international standards for training in cardiac pathology [AECVP & SCVP]
  - Master’s programme in Cardiac Pathology, Padua, Italy (*Professor Gaetano Thiene*, [cardpath@unipd.it](mailto:cardpath@unipd.it)) [annually])
  - Royal Brompton Practical Cardiovascular Pathology
  - Others………………
Annual UKCPN training days

• Annually in June, venue Birmingham
• Mix of invited talks, audits and case presentations
• Topics covered
  - How to …….HCM, ARVCM, conduction system, “dodgy deaths”
  - Audit series from Royal Brompton, Oxford, Wirral, Great Ormond Street, Papworth
  - What is it? 26 presentations in 4 meetings
  - Inaugural Olsen-Gourley Lecture (2009), PathSoc-sponsored talks
• Future topics?
  - Case reviews using digitised slides
  - SD and obesity
  - SD and alcoholic liver disease
  - DVD demonstrations as for ESP
Publications

- RCPPath Scenario 1 (2005). Sudden death of probable cardiac origin
- RCPPath Tissue Pathways [Dr. J Boyle & team] (2008)]
  http://www.rcpath.org/publications/
  *Virchows Arch* 452(1):11-18
- Soilleux E and Burke M (2009) Pathology and investigation of potentially hereditary sudden cardiac death syndromes in structurally normal hearts
SADS database

- Version 1.0 launched by DOH in November 2008
- Set up under auspices of Central Cardiac Audit Databases [CCAD]
- Funded by DoH for 2 years from April 2008
- Version 2.0 for launch Dec 09
- Annual report by June 2010

- Approval to collect patient-identifiable data for secondary use given by NIGB via Ethics & Confidentiality Committee exemption from Section 251 of NHS Act 2006
- PIAG-approved information leaflet for families available

- Web-based, password-protected database
- Use of data strictly controlled
- Users can access their data and summary data at behest of SG
- Academic Committee will define research projects using data
SADS database
http://www.ncasp.org.uk

Inclusion criteria

Sudden cardiac death due to non-ischaemic non-valvular heart disease

LV Hypertrophy not due to known or suspected HT

Age range 0 - 65yrs

Excludes SIDS
Report December 2009
Submissions

- Brompton: Total (160), since Jun '09 (26)
- Harefield: Total (10), since Jun '09 (2)
- Southampton: Total (40), since Jun '09 (1)
- Gloucester: Total (30), since Jun '09 (1)
- GOS: Total (10), since Jun '09 (1)
- Wirral: Total (5), since Jun '09 (1)
- Whiston: Total (5), since Jun '09 (1)

Total submissions (212) since June 2009 (26).
Time of death
(known in 20%)
Age
mean 36.0
median 34.2
Circumstances

- In bed: 28%
- At rest: 28%
- Unknown/not recorded: 23%
- Emotional state: 2%
- Severe exertion: 5%
- Moderate exertion: 8%
- Mild exertion: 6%
Comorbidity

- Epilepsy: 2%
- Asthma: 8%
- Congenital heart disease: 4%
- Other: 29%
- Unknown/not recorded: 57%
Family History

- Unknown/not recorded: 87.3%
- Premature sudden death: 5.7%
- Diabetes: 0.5%
- Other: 5.7%
- Cardiomyopathy: 0.9%
Pathology Images

- Submitted in only 8 cases
The UKCPN Website
http://www.ukcpn.org.uk
DISTRICT GENERAL AND FORENSIC PATHOLOGISTS

If you do a large number of coronial autopsies and you wish to keep up to date on aspects of cardiac autopsy pathology please consider joining

*************************************************************************
THE UK CARDIAC PATHOLOGY NETWORK
(established December 2006)
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We provide protocols for detailed investigation of certain cardiac conditions leading to sudden death, with additional information to help you in advising coroners and communicating with bereaved families

We encourage registration of selected cases on a national database for future audit and research, and a dedicated website (www.ukcpn.org.uk) for sharing of protocols, updates and problem cases.

If you are interested, please e-mail

Dr. Michael Ashworth, Great Ormond Street Hospital
AshwoM@gosh.nhs.uk

or

Dr. Patrick Gallagher, Southampton General Hospital
pj.gallagher@soton.ac.uk