

# The role of specialist nurses in cardiac genetics - the Victorian experience: supporting partnerships in care

## AUTHORS

### Tina Thompson

B.Nurs. Nurse Specialist - Genetic Medicine. The Royal Melbourne Hospital, Grattan Street, Parkville, Victoria, Australia.

Tina.thompson@mh.org.au

### Natalie Morgan

RN, Crit Care Cert, Grad Dip Genetic Counselling. Medical Liaison Nurse. Victorian Institute of Forensic Medicine, Kavanagh Street, Southbank Victoria, Australia.

Natalie.morgan@vifm.org

### Vanessa Connell

Dip App Sci (Nursing), Grad Dip Adv Clinical Nursing (Paediatric Intensive Care). Clinical Nurse Consultant – Electrophysiology. The Royal Children's Hospital Melbourne, Flemington Road, Parkville, Victoria, Australia.

Vanessa.connell@rch.org.au

### Dr Dominica Zentner

MBBS(Hons), FRACP, PhD. Consultant Cardiologist, The Royal Melbourne Hospital, Grattan Street, Parkville Victoria, Australia.

Dominica.zentner@mh.org.au

### Associate Professor Andrew Davis

MBBS, MD, FRACP, FCSANZ, FHRS. Paediatric Cardiologist and Electrophysiologist. The Royal Children's Hospital, Flemington Road, Parkville; Murdoch Children's Research Institute and The University of Melbourne, Victoria, Australia.

Andrew.davis@rch.org.au

### Dr Andreas Pflaumer

MD, FRACP, FCSANZ, CEPS. Consultant Cardiologist/ Electrophysiologist, The Royal Children's Hospital, Clinical Senior Lecturer University of Melbourne & Honorary Fellow Murdoch Children's Research Institute, Victoria, Australia.

Andreas.pflaumer@rch.org.au

### Professor Noel W F Woodford

MBBS LLM DMJ(Path) FRCPPath FRCPA. Professor of Forensic Medicine, Monash University & Director, Victorian Institute of Forensic Medicine Kavanagh Street, Southbank, Victoria, Australia.

Noel.woodford@vifm.org

### Professor Ingrid Winship

MBChB, MD, FRACP, FACD. Professor - Adult Clinical Genetics. The Royal Melbourne Hospital, Grattan Street, Parkville, Victoria, Australia.

Ingrid.winship@mh.org.au

## KEY WORDS

partnerships; cardiac genetics; sudden unexplained death; screening; specialist nurse

## ABSTRACT

### Objective

In Victoria, Australia, a unique referral process exists for families who require investigation for possible inherited cardiac disease. This is spearheaded by a team of specialist nurses located at the Royal Children's Hospital Melbourne (RCH), the Royal Melbourne Hospital (RMH) and the Victorian Institute of Forensic Medicine (VIFM), who ensure that all potentially at-risk families are offered the opportunity for clinical assessment and consultation.

### Setting

In Victoria, approximately 5,500 deaths are reported to the Coroner each year. Where there is a suspicion of a causative heritable cardiac condition, the surviving relatives are offered referral to a tertiary centre for assessment and screening.

### Subjects

A specialist nurse employed by the VIFM is the focal point for forensic pathologists to flag families requiring referral. Concurrently, specialist nurses within the cardiac genetic services of RMH and RCH accept, review, triage and action these referrals. All three services work closely to create a seamless model of care, which is age appropriate and provides ease and equity of access to consistent care.

### Primary argument

The nurse specialists are a critical part of the multidisciplinary team, providing the first entry point into the hospital system. Their background experience encompasses intensive care and cardiology nursing. This is essential to the provision of professional and empathetic care in which families can approach the difficult issues surrounding post mortem consideration of a diagnosis.

### Conclusion

The Victorian nurse led system is an effective model, which could be trialled in other jurisdictions, and other disorders, where multidisciplinary care is required.

## INTRODUCTION

In 2004, a nurse-initiated referral process for families requiring cardiology screening began between The Royal Children's Hospital (RCH) and the Victorian Institute of Forensic Medicine (VIFM). This service to the Victorian public arose from a perceived need for specialised care and a systematic approach for at risk families, and was expanded in 2007 with the establishment of the Cardiac Genetics Clinic at The Royal Melbourne Hospital (RMH).

Prior to establishing the current service, at-risk families were referred to General Practitioners (GP) with a recommendation for follow-up and screening. It became evident that it was difficult to determine whether this approach was effective and whether at-risk relatives were being adequately managed. Therefore, the Victorian Institute of Forensic Medicine ran a pilot program with 15 families who were referred to a specific medical specialty (Morgan 2005). After trialling a targeted referral process, participants were asked to complete a survey. As a consequence of the positive feedback from families, pathologists and other staff, the pilot evolved into the formalised referral service it is today.

The aim of this service is to identify and manage cases of potentially preventable cardiac deaths by a process of early referral, consistency of information collation and provision, and coordinated care between adult and children's services.

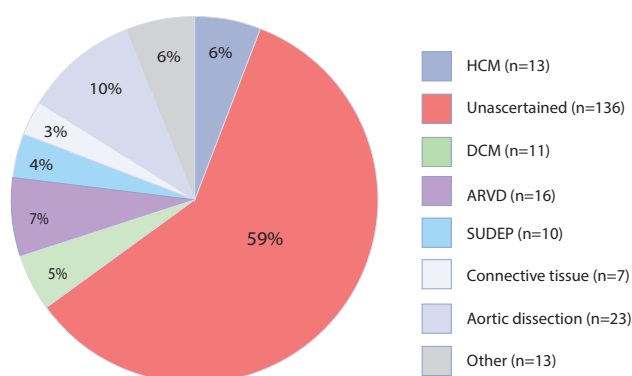
When there is suspicion of a causative heritable cardiac condition, the surviving relatives are offered referral to a tertiary centre for assessment and screening. These cases include, but are not limited to, deaths where the cause is unascertained, hypertrophic cardiomyopathy (HCM), dilated cardiomyopathy (DCM), aortic dissection, arrhythmogenic right ventricular dysplasia (ARVD), sudden unexpected death in epilepsy (SUDEP), connective tissue disorders and cardiomegaly.

In Victoria, a unique team of nurses lead this system to ensure that all potentially at-risk families are offered the opportunity for clinical assessment and consultation. These specialist nurses have appropriate clinical expertise and knowledge, with cross-disciplinary knowledge of both genetic medicine and clinical cardiology.

A specialist nurse employed by the Victorian Institute of Forensic Medicine (VIFM) provides the focal point for forensic pathologists to flag families requiring referral. This position is pivotal in contacting families, using established clinical skills to ascertain important information and relevant history of both the deceased individual and their family members in a socially sensitive manner. This expertise is critical in identifying cases where genetic testing may be accessible and relevant at a later date; thereby ensuring appropriate samples for DNA extraction are obtained and stored.

Family members who accept referral to the Cardiac Genetic Clinics receive a seamless, specialised and integrated model of care, which is age appropriate, and delivered at either, or both the Royal Melbourne Hospital (RMH) and Royal Children's Hospital (RCH). The Victorian model promotes and provides ease and equity of access to consistent care, with clinicians able to discuss and share information (with consent) across both campuses.

A number of conditions are referred post mortem by VIFM. Figure 1 details the post mortem diagnosis in all the cases where adults were referred to the RMH from mid 2007 to mid 2014. The largest proportion is sudden cardiac death, without further diagnosis as to the cause at autopsy, a condition where the death certificate is issued with the cause of death being 'unascertained'.

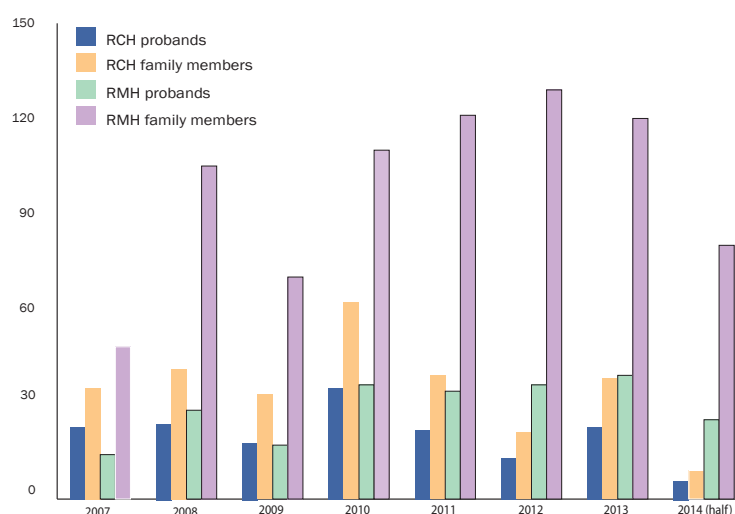


**Figure 1: Diagnoses at VIFM where referral made to a Cardiac Genetics Service at RMH**

In terms of referral numbers, the diagnosis for referral fluctuates from year to year. After an initial rise in referral numbers and as the Victorian model matured, figures have remained constant over the last few years (figure 2). The number of family members referred for screening after a sudden cardiac death (SCD) is dependent on family size, structure, age of the proband (the index case) and how many first-degree relatives accept referral.

On average, a referral to RCH results in 1.7 family members being screened and to RMH results in 3.4 family members screened per proband (figure 2). This reflects the overall smaller number of relatives aged less than 18 in comparison to those that are adult. To date, 758 individuals in 229 have been referred via this route for diagnosis, risk assessment and risk management to RMH alone. At RCH, 164 families including 278 children have had the opportunity for screening for heritable cardiac conditions.

**Figure 2: Comparison of the number of individuals (probands/index case) and family members referred from VIFM to RCH & RMH each year (2007 – July 2014)**



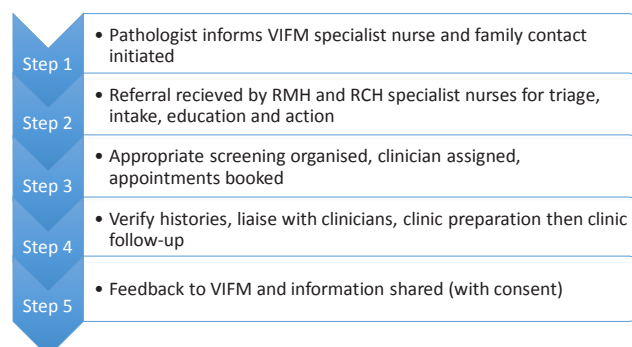
## DISCUSSION

The referral process that has been established and run by the specialist nurses is simple and effective. The specialist nurses review, triage and action the referrals. They document and verify family histories, organise appropriate pre-assessment clinical screening and manage clinic bookings to ensure optimal use of the clinician and patient time. Clinical liaison is a central role for all specialist nurses.

Throughout the referral, screening and feedback process all three clinical services work closely and cohesively. Communication amongst the groups is critical – especially with shared families. Regular clinical meetings between all centres provide an opportunity for open and honest feedback and an opportunity to seek further clinical information.

Record keeping, consent, storage of appropriate biological samples and the content of post mortem reports are just a few things that have become streamlined as the result of this approach to feedback.

The main pre attendance steps and clinical pathway are detailed in figure 3.

**Figure 3: The referral steps and clinical pathway**

The nurse specialists provide the initial contact with families and facilitate entry into a multidisciplinary clinical care setting. The nurses involved have clinical expertise in cardiology nursing (n=3), coronary care/ICU nursing (n=3) and worked at VIFM (n=2). The cross-disciplinary knowledge and experience allows them to fulfil many essential roles within the clinical services and enables effective communication (figure 4) with the inter-professional team.

In addition to clinical service, the nurse relationship between VIFM, RMH, and RCH has provided an effective platform for research studies and the translation of research findings into clinical practice. Recruitment of patients to The National Genetic Heart Disease Registry (Ingles et al 2008) and the Investigation of Sudden Cardiac Death in the Young study are just two examples of this.

## CONCLUSION

Having a single point of contact identified in each service has provided a consistent level of service provision, and fosters expertise and accountability. The specialist nurses have multiple functions and responsibilities within their respective organisations, but together form part of a larger team that aids in the clinical care of Victorian families who have suffered a recent, and sometimes unexplained, bereavement in a sensitive and effective manner.

Collaboration between specialist nurses in the individual services has created streamlined access to medical specialists, providing the basis of multi disciplinary care and managing identification and transfer of samples suitable for DNA extraction. The relationship between VIFM, RMH, and RCH has aimed to provide equitable, easily accessible and age appropriate care to the potentially at-risk people of Victoria, in the area of cardiac genetics.

Audits of parts of the Victorian service have been published elsewhere (Kumar et al 2013). Further auditing of the services is now underway to assess adherence to screening recommendations and recall of advice given as a marker of the effectiveness of the clinic.

## RECOMMENDATIONS

The authors believe that the Victorian nurse led system is an effective model. It is proposed that the model could be adopted in other Coronial jurisdictions and could be applicable to other disorders requiring multidisciplinary care.

**Figure 4: The many roles of the specialist nurse**

In the future, these specialist nurses being recognised as part of advanced practice nursing, is a real possibility. As the framework for advanced nursing practice is formalised, ways of assessing the practice of specialist nurses is essential in the dynamic, unpredictable and ever-changing world of healthcare and service provision.

## REFERENCES

Ingles, J., McGaughran, J., Vohra, J., Weinrub, R.G., Davis, A., Atherton, J. and Semsarian, C. 2008. Establishment of an Australian National Genetic Heart Disease Registry. *Heart Lung Circulation*, 17(6):463-467.

Kumar, S., Peters, S.M., Thompson, T., Morgan, N., Macciocca, I., Trainer, A., Zentner, D., Kalman, J.M., Winship, I. and Vohra, J.K. 2013. Familial Cardiological and Targeted Genetic Evaluation: Low Yield in Sudden Unexplained Death and High Yield in Unexplained Cardiac Arrest Syndromes. *Heart Rhythm*, 10(11):1653-1660.

Morgan, N. 2005. VIFM Family Health Information Service. Unpublished report. Southbank, Australia.