

# Working to improve care for patients and families affected by inherited cardiomyopathies

Following the recent articles published in the *British Journal of Cardiac Nursing* illustrating the complex needs of patients and families affected by hypertrophic cardiomyopathy (HCM) (Bellchambers et al. 2017; Wassall et al. 2017), it is clearly high time that clinical services are improved to meet this demand. The British Association for Nursing in Cardiovascular Care (BANCC) supports nurses to deliver service improvement projects by providing a forum via which they can successfully carry these out.

**Tootie Buaser**, President-elect of BANCC and Lead Nurse for Inherited Cardiac Conditions (ICC) at King's Health Partners (KHP) (the Academic Health Science Centre encompassing Guy's & St Thomas' NHS Foundation Trust and King's College Hospital NHS Foundation Trust) talks about how she has been working closely with other KHP ICC leads, Dr Gerald Carr-White and Dr Leema Robert; her local ICC patient and public involvement (PPI) group, the British Heart Foundation (BHF) and patient support groups; to deliver a comprehensive model of care for those affected by HCM across Southeast London and Kent:

In 2008, we started our ICC service with one clinic a week at each hospital site; now, we are seeing over 5000 patients a year

within the region and nationally. With HCM having an incidence of 1:500 (Burton 2009), this is by far our biggest patient population. While it is a privilege to be a leading centre of expertise for ICCs, much can be improved—particularly along the patient pathway, given the genetic and long-term nature of the condition. We were already adhering to published guidelines (Elliott et al. 2014), but we also wanted to know what patients wanted out of the service. We conducted PPI activities with our patients and their families, and also involved the patient support group, Cardiomyopathy UK ([www.cardiomyopathy.org](http://www.cardiomyopathy.org)). What came out of this exercise was a comprehensive patient 'wish list', and their feedback on their experience of care. This included access to a one-stop expert tertiary level ICC clinic, more support and comprehensive information before, during and after clinic visits for their physical and psychosocial needs (as well as their families'). They also discussed the practicalities of their long-term follow-up and how some care can be delivered locally, but if they develop more complex needs, they can easily access the specialist clinic.

We consolidated this feedback and developed a proposal which was presented to the BHF following their funding call for service innovation through the Miles Frost Fund. This fund was established by the Frost family following the tragic death of Miles Frost from undiagnosed HCM which was likely to be inherited from his father (BHF 2017). Our successful application to this fund has now made it possible to employ a full-time ICC specialist nurse and pathway coordinator who will deliver the vision for comprehensive care for HCM patients and their families in the region. This includes a hub-and-spoke model where the KHP 'hub' will provide the expert diagnosis and management plan, alongside genetic counselling, testing and patient and family support. The specialist nurse and pathway coordinator will facilitate the development and upskill-

ing of the 'spokes' in district general hospitals who can provide routine long-term follow-up and ensure family screening and/or cascade genetic testing. We will also continue to signpost to support groups, like Cardiomyopathy UK, which provide valuable practical information and connections for our patients.

This project is also a perfect opportunity to gauge the impact of mainstreaming genetics into clinical practice as the outputs of the 100 000 Genomes project come to the fore. We will be closely monitoring the progress and milestones of this project to ensure it is effective, viable and acceptable to patients. Most of all, we want to make sure this is in keeping with the spirit of the BHF Miles Frost fund, which is to promote early diagnosis and management; and the prevention of sudden death in HCM.

Often, in a push to improve clinical services, the NHS requires additional resources to help projects take seed before they are adopted for routine practice. Beyond sheer numbers and the voice of clinicians, working with patients, families, support groups and charities, is the way forward in driving health-care innovation. **BJCN**

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