Abstract

Postmortem genetic testing provides an opportunity to clarify the etiology of sudden death cases and can clarify the risk of disease for family members. The unique challenges of this type of testing result in questions from the medical community and family members. The National Society of Genetic Counselors (NSGC) Postmortem Working Group (PMWG) was formed to address queries about postmortem genetic testing in a consistent and efficient manner. The PMWG launched an email address in October 2013 to address queries about postmortem genetic testing. Postmortem genetic testing is performed on a limited DNA specimen in a forensic setting. In an effort to improve access to genetic testing for the medical examiner, genetic counselors and nurses navigating the complex path of genetics, the PMWG was formed through the National Society of Genetic Counselors (NSGC).

Methods

In 2013, shortly after the NAME publication, a Postmortem Working Group (PMWG) was formed through the National Society of Genetic Counselors (NSGC). The purpose of the PMWG is to increase awareness of proper specimen collection and storage following an autopsy and to act as a resource for all involved in the postmortem genetic testing/DNA banking process.

Resources

Anticipating existing questions within the ME field and amongst family members whose loved ones have died suddenly, the PMWG developed a webpage through the NSGC dedicated to postmortem genetic testing in October 2013. Staffing

Seven GCs rotate through a monthly call schedule replying to queries that are received through the PMWG email address. Staffing of the PMWG has expanded to include eight consultant GCs specializing in prenatal, epilepsy, and metabolism, reflecting the relevance of postmortem genetic testing across subspecialties.

Tracking

Queries to and replies from the PMWG email have been tracked since its inception. A Google Form and spreadsheet are used to track each query, including the question, GC responder, nature of the query and subsequent referral to genetic services (if applicable). Actual email correspondence is recorded as well.

Results

Since launching the PMWG email in October 2014 to March 2017 (30 months), the PMWG has received 34 email inquiries from a variety of sources (see Figure 1).

Conclusions

The utilization of postmortem genetic testing provides a promising avenue to clarify the cause in sudden death cases. The use of postmortem genetic testing is increasing among the medical examiner community, and will likely continue to do so with continued educational efforts about the process and reduced costs of genetic testing. In addition, the application of postmortem testing to multiple subspecialties (including cardiology, neurology and metabolic), and protocols that are being developed to identify, standardize and understand the causes sudden death will lead to greater uptake. Genetic counselor access through the mechanism of email has shown to be effective in fielding calls from the postmortem community. Queries to the email most often involve guidance for family members of decedents seeking a cause of death for their loved one, and logistical expertise provided to medical examiners, genetic counselors and nurses navigating the complex path of postmortem testing. The PMWG will continue to track the email inquiries and continue to educate those involved in postmortem genetic testing to help make the process easier for all. This model is proposed as one method for genetic counselors to share their expertise with a specialty disease community in the setting of limited genetic counselor availability.

References


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