

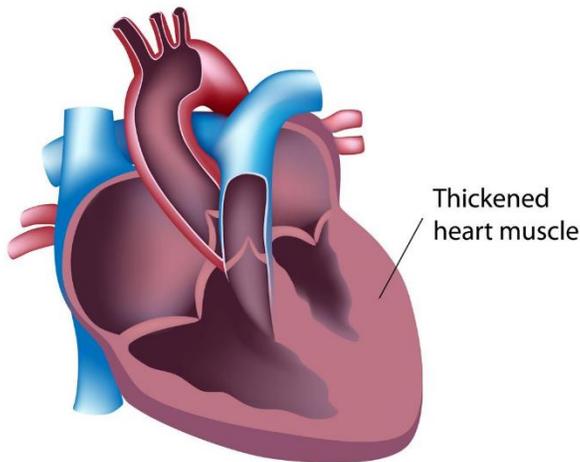
How One Serves Our Amish Community – Hypertrophic cardiomyopathy Screening

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Genetic disease is one of the most prominent health issues in Amish communities. Since the Amish do not marry outside their community, they have retained a closed genetic population with a limited gene pool for more than 10 generations (Wang, Heng and Baozhong, Xin, May 2011, pg.130). Hypertrophic cardiomyopathy (HCM) is a genetic disorder common to the Amish population and is characterized by left ventricular hypertrophy unexplained by secondary causes, and a non-dilated left ventricle with preserved or increased ejection fraction (Marian, Ali J. and Braunwald, Eugene, September 2017, pg.749). In many cases, HCM can be relatively benign, however, it can be attributed to sudden cardiac death, particularly in adolescents and young adults (Marian, Ali J. and Braunwald, Eugen, September 2017, pg.749).

██████████ Pennsylvania is a borough of 300 people in the northeastern section of ██████████ County and is home to many Amish families. In one Amish family from ██████████, it was discovered that there was a genetic predisposition to HCM. This realization came to be after a young Amish man died of sudden cardiac death and the pattern was seen within the family pedigree. Through word of mouth in the community, many of the extended family members within the bloodline have sought evaluation and treatment for HCM at UPMC Presbyterian's Heart and Vascular Institute.

Hypertrophic cardiomyopathy



As an ethnic group, the Amish communities do not use cars, telephones, or electricity; they often live in rural areas with limited access to medical services (Wang, Heng and Baozhong, Xin, May 2011, pg. 130). Because of these limitations, **Kimberly Castro, BSN, RN**, senior professional staff nurse, BSN, is instrumental in her role as Outpatient Nurse Coordinator. She has embraced the care of the Amish population by connecting via the Amish “message line” to coordinate appointments for multiple family members who must travel over two and a half hours to be seen by **Dr. Timothy Wong**, Cardiology. Ms. Castro actively participates in the patient intake process and assists with ensuring the patient is billed under a discounted “Amish” rate.

In support of the Healthy People 2020 goal to “*Improve access to comprehensive, quality health care services*”. Ms. Castro traveled to ██████████ with her HVI colleagues: Dr.

Wong, faculty – cardiology physician; **George Cater**, graduate cardiology fellow VI; **Amy Brownell**, clinical project director; and **Meredith Jones**, senior genetic counselor. The team volunteered their time to complete additional HCM Screenings for Amish family members in the ██████████ family home. Three and one-half hours were spent screening 24 extended family members for HCM.

The project began through the inspiration of Dr. Wong and his work with the Amish HCM patients and was supported by Heart and Vascular Institute's Senior Leadership. Supplies were donated and the portable ultrasounds were borrowed for use from the HVI Clinic. Physician volunteers donated their time to perform cardiac ultrasounds on family members in attendance. Clinical volunteers such as the Registered Nurses (RN) were needed to perform health screenings in medical triage which included a comprehensive history, blood pressure, pulse, respiration, temperature, and oxygen saturation. A genetic counselor was on hand to answer questions.