

## **Improving Heart Disease Knowledge and Research Participation in Adults with Congenital Heart Disease (The Health, Education and Access Research Trial: HEART-ACHD)**

**Background:** Many adults with congenital heart disease (ACHD) lack knowledge about their heart condition which may contribute to worse outcomes. We undertook a prospective multi-center study to evaluate heart disease knowledge, pilot an educational intervention and assess interest in research participation among new patients at ACHD clinics.

**Methods:** A study cohort was created by recruiting adults ( $\geq 18$ y) upon their first presentation to an ACHD clinic from 2009–2010. Subjects completed an initial survey regarding heart disease knowledge and interest in research participation. Each subject then underwent an educational intervention consisting of creation of a personal health information ‘passport’ and an introduction to web-based resources. Subjects were asked to complete a follow-up survey 3 months later. Other variables collected included gender, race, ethnicity, education level, and up to 5 congenital heart diagnoses.

**Results:** We recruited 922 subjects (54% female, 83% white/non-Hispanic) from 12 ACHD centers. Follow-up surveys were completed by 535 subjects (57%; 57% female, 85% white/non-Hispanic). Patients who completed the follow-up survey were more likely to be women, have more education, and have mild heart disease. At follow-up, the ability of the subjects to name their heart condition improved (78% v. 83%,  $p=0.002$ ). Significant improvements were also seen in mean Likert scores when subjects were asked if they understood appropriate exercise ( $p<0.0001$ ), symptoms of heart rhythm problems or endocarditis ( $p<0.0001$ ), reasons for cardiac tests ( $p<0.007$ ), birth control options and pregnancy safety ( $p<0.0001$ ). Over half of subjects found the passports easy to use and helpful, however website use was limited. On follow-up, subjects reported a better understanding of medical research ( $p<0.01$ ), a higher likelihood of research participation ( $p<0.003$ ) and a greater awareness of current projects ( $p<0.0001$ ).

**Conclusion:** ACHD subjects were able to improve gaps in knowledge about their heart disease with a simple educational intervention. Subjects also showed a greater understanding of the process of medical research and expressed interest in future research participation.