Improving Pregnancy Outcomes in Women with Tetralogy of Fallot

Most women with repaired tetralogy of Fallot (rTOF) reach childbearing age and seek counseling regarding the consequences of pregnancy on their health and the health of their offspring. However, there is very little data to guide clinicians in the risk-assessment of these women. The data that is available is mainly focused on the immediate risks during pregnancy, and the long-term effects of the heart sustaining the increased workload of pregnancy is unknown. The majority of patients with rTOF have leakage of the pulmonary valve, known as pulmonary regurgitation, which may lead to large right ventricles (RV) that have decreased efficiency. Cardiac magnetic resonance (CMR) is an imaging tool that is useful to document the size and function of the RV. Clinical guidelines recommend that pulmonary valve replacement (PVR) be considered in rTOF that meet specific clinical criteria. However, it is unknown whether there is a benefit from recommending PVR in women with rTOF before pregnancy in hopes to limit the effects of the increased workload to the heart on the RV size and function.

In an effort to address these critical questions, we propose an investigation to be performed over two years at two large adult congenital heart disease centers. The goal of this investigation is to collect data that will allow for a better understanding of the effects of pregnancy in women with rTOF. Our approach will be to review the available data on women with rTOF who have undergone pregnancy and compare their RV size and function to women with rTOF who have not undergone pregnancy. By partnering with the Toronto Congenital Cardiac Centre for Adults, we can specifically evaluate a group of women with rTOF and PVR who have undergone CMR both before and after pregnancy and compare their findings with women with rTOF who have not had a PVR. We will also examine the mother and baby’s clinical course and document any problems that occurred during pregnancy. This data will be helpful to help guide women in the decision of timing of PVR. Lastly, in order to better understand the suspected changes that pregnancy places on the hearts of women with rTOF, we have developed an initiative to bring women back within three months of the baby’s delivery to perform CMR and a test of exercise endurance. Recognizing the challenges of women returning for these studies, we have specially developed a plan to include each woman’s preference as to the timing of testing and provide a stipend for childcare and transportation on the day of testing. It is our hope that this investigation will provide the information needed to better counsel women with rTOF who desire pregnancy. We believe that this project advances the mission of the Adult Congenital Heart Association (ACHA) to improve and extend the lives of the millions born with heart defects and address the research priority of the ACHA by collaborating with patients for better health outcomes.