



**Boston Children's Hospital**  
Until every child is well™

**Departments of Cardiology  
and Cardiovascular Surgery**

March 30, 2017

Dear Ms. Ashford,

We are contacting you today to let you know about a study being conducted at Boston Children's Hospital. Both the Cardiology and Cardiac Surgery departments are not only active in treating our patients but also in promoting research in order to understand and find better ways to treat medical conditions.

With the support of the Ebstein's Foundation my colleagues and I are looking at the Cone operation in Ebstein's Anomaly and to determine how these patients are doing over time. As a member of the research team, I am contacting all patients who have undergone a Cone repair at our hospital, and asking each to be a part of this study. The purpose of this study is to better understand the long term cardiovascular and quality of life changes after the Cone repair. The name of the study is **Anatomic, hemo-dynamic and quality of life results of the Cone operation for Ebstein's malformation of the tricuspid valve.**

For the study we would like your permission to contact your cardiologist and ask him/her to send us the clinical information about you or your son/daughter as pertains to the Cone operation. This would include sending a recent clinical letter, and the results and images of echocardiograms, electrocardiogram (ECG), MRI and exercise tests. If you have not done these tests recently, we will ask your cardiologist to consider obtaining these tests, and then send us the images and results of these tests. We also want to learn about you or your child's quality of life. We would also like your permission to send you or your son/daughter a questionnaire regarding your quality of life. This questionnaire will take no longer than 15 min to complete, and can be returned in provided stamped envelope.

**If you are interested in learning more about participating in this study please feel free to contact Dr. Gerald Marx at 617-355-0039 / Gerald.Marx@cardio.chboston.org or Dr. Mariana Chávez at 617-355-3515 / Mariana.Chavez@childrens.harvard.edu. If you do agree to participate please complete the enclosed informed consent (you can send only signed pages), questionnaire, and mail it back in the pre-paid envelope.**

It is important to know that this letter is not to tell you of your need to participate in this study but again to ask permission to obtain information about your clinical status and quality of life. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with Boston Children's Hospital as a patient.

You are not required to respond if you've decided to not participate in this study. If you do not respond, you may receive another letter in the mail which you can simply disregard.

Thank you for your consideration and time. We look forward to hearing from you.

Sincerely,

Mariana Chávez Rodríguez, MD  
Research Fellow  
Department of Cardiac Surgery,  
Boston Children's Hospital  
Office: 617-355-3515.