

**From:** Weinstock, Victoria <Victoria.Weinstock@chtrust.org>  
**Sent:** Monday, January 23, 2023 10:53 AM  
**To:** Arden Ashford <ardenashford@gmail.com>  
**Cc:** Robert Ashford <ashford66@gmail.com>  
**Subject:** Updates from Dr. Marx and team

Hello Arden,

I hope you had a wonderful weekend! Again, please accept my sincere apologies for the delay in getting you this information. Dr. Marx and his research team are so grateful for your family's generous support over the years, which has made a tremendous impact on the treatment and understanding of Ebstein's Anomaly.

As you know, your support has helped the team pursue treatment options for this condition and is currently studying the impacts of the Cone operation. Since Dr. Marx last updated you, the team has consented and obtained important data on an additional 60 patients who have undergone the operation. Data collected and analyzed is focused on physical health measures such as echocardiograms, exercise tests, electrophysiology results, MRIs, and caths; as well as the quality of life measures, such as psychological condition and more. While the team continues to gather this data, it will be important information to share with the Ebstein's Anomaly community and provide insight into treatment outcomes.

In addition, the team is currently designing an electronic consent and survey platform to reach more patients. This will increase enrollment in this study and lead to greater efficiencies in data analysis. Looking ahead, the team hopes to launch the surveys and collect data from more patients, leading to a greater comprehension of the Cone operation and Ebstein's Anomaly. With this information, researchers will analyze the data to provide important implications and insight into the operation, which they will share in scientific papers. As one of the only pediatric institutions conducting the Cone operation, we feel responsible for sharing this data with the world.

None of the above would be possible without your generous support. Your family has been valued partners in our work to improve the quality of life for so many children and adults with Ebstein's Anomaly, and we hope to continue this partnership this year.

Please let me know if you have any questions or would like additional information. Additionally, I know you were in Boston around this time last year, so let me know if you are planning on coming up again and need any assistance. If so, I'd love to grab coffee!

With gratitude,  
Tori

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