

The Roya Kabuki Program  
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## **eConsenting with the Roya Kabuki Program**

Beginning in October, 2020, the Roya Kabuki Program is excited to have an expanded research consenting capability that now includes an electronic consenting process. Our study protocol and related consent forms are now available through a HIPPA compliant secure system called REDCap (Research Electronic Data Capture BCH eConsenting platform). This platform will allow Roya Kabuki Program participants to view forms and provide electronic consent remotely on their home computers and/or mobile devices.

The eConsent process will eliminate the need for mailing paper copies of consent forms and reduce the overall time of the consent process. Participants opting to eConsent will receive a unique link to the study consent form and have a chance to review, ask for clarification, and provide an electronic signature. If a participant completes a portion of the consent form, they will be able to save their progress and return at a later time. We will still set up a phone call with a member of the study team to confirm comprehensive understanding and consent for research participation. Participants will receive a PDF copy of any completed forms.

### **Who can use the eConsent platform?**

Any participant who wishes to learn more, or is in the process of learning about, the Roya Kabuki Program may use the eConsenting platform. If a participant has already provided consent using paper forms and wishes to complete an additional study consent form after October 2020 via eConsent may do so.

### **How to contact The Roya Kabuki Program to start the eConsent process?**

Thank you for considering participation opportunity. We hope this information helpful. If you have any questions about the eConsenting process, or want to begin, please contact us at 857-218-KBKI (5254) or email [kabuki@childrens.harvard.edu](mailto:kabuki@childrens.harvard.edu).

Our research would not be possible without the generous and selfless participation of people and families like you.

Sincerely,

Olaf Bodamer MD, PhD, FAAP, FACMG  
Director of the Roya Kabuki Program Clinical Chief of Genetics and Genomics

Tara Daly, MsC  
Roya Kabuki Program Coordinator ([kabuki@childrens.harvard.edu](mailto:kabuki@childrens.harvard.edu))