

RI-CART TRANSITION QUESTIONS

If you have an additional question about your participation in RI-CART send us an email RICART@lifespan.org



- **What happens with my participation now that RI-CART is pausing enrollment for new participants?**

While we're pausing enrollment for new participants, our research assistants will be working to organize and optimize our data base so that researchers may find information for their studies. RI-CART researchers are continuing to analyze the data and information that has been collected and are preparing manuscripts for scientific journals. These tasks are part of our continued effort to work together, advancing our knowledge of ASD.

- **When I participated in RI-CART I gave biosamples. What happened with this samples? Are we receiving any results?**

RI-CART participants have generously shared biological samples (blood samples or saliva) as part of enrollment in the consortium. We now have thousands of samples, including both participants with ASD and their family members. We are actively working with our primary funder to process and analyze these samples. The main purpose of these types of tests is understanding more about the genetics of ASD and developmental disabilities. We will let participants know as a group when the genetic analyses of the RI-CART samples are completed. This is a complex process and we are working with our funder to define a timeline. Because this testing will be done by a research laboratory, these research analyses cannot serve as a clinical test, so individual participants will not receive specific results directly from us. This is because the analyses are not performed by a clinical laboratory with certified procedures for reporting results to patients.

- **I have some documents pending to send. Should I still send them?**

YES! Please send any documents that you are completing. We really appreciate the time that you took to participate in our research study and fill out the surveys and questionnaires. As we transition to this new phase, it is very important for us to have your complete and updated information, which will allow us to advance in the process or learning more ASD in Rhode Island. We encourage you to finish the documents and send them to us as soon as possible. If you have questions, please contact us and one of our research assistants can help you (our phone number is 401-432-1200).

- **While new enrollment is on hold, will my information be available for other studies? Should I expect to receive additional calls to offer enrollment in future research as you mentioned initially?**

New enrollment is paused, but RI-CART is still in operation, and that includes helping connect participants to research studies. This “matchmaking” role is an important part of our partnership with the community. If you agreed to be recontacted for other research, as a RI-CART member, you can continue participating in future research studies. Different studies have different criteria, and if your profile matches and you agreed to participate in additional research, a member of our team may call you and let you know. Of course, you can choose whether or not you want participate.

- **If I move or I change some of my information, what should I do?**

We want to keep in touch and to be able to share important information with you in the future. You can contact us by phone 401- 432-1200 or by email at RICART@LIFESPAN.ORG. It's important for us to have your updated information as we periodically send communications about events around RI, talks, and new services and or other information that could be relevant for you and your family.

- **I have friends, family, or patients who would be interested in participating Can they still get in contact with RI-CART?**

The RI-CART website remains active and is a great place for information about the project and about community resources. Families can visit the website to learn about the project and to find out when enrollment opens up again. Visit www.autismRI.org to learn more!

