



Return of Results parent follow-up survey

Post Data-Return Survey

Thank you for participating in the 'return of patient data' study.

Now that you have received information on your son and the results of the vamorolone clinical trial, we would appreciate your feedback on this process, and how important or useful this information was to you.

1. Please answer the following questions.

How important was it to you to receive your child's individual clinical trial results?

- ☐ Not important
- ☐ Somewhat important
- ☐ Important
- ☐ Very important

2. If it was important to you to receive your son's data, why was this important to you?

You may skip this question if it does not apply.

3. How important was it to you to receive a summary of the results from other children in the trial?

- ☐ The most important priority
- ☐ A top priority, but not the most important
- ☐ Not very important
- ☐ Not important at all

4. If it was important to you to receive a summary of data from other trial participants, can you tell us why? You may skip this question if it does not apply.

5. How satisfied were you with the delivery of data on an encrypted USB drive by mail?

- | | |
|--|---|
| ☐ Very satisfied | ☐ Somewhat dissatisfied |
| ☐ Satisfied | ☐ Dissatisfied |
| ☐ Somewhat satisfied | ☐ Very dissatisfied |
| ☐ Neither satisfied nor dissatisfied | |

6. The amount of information provided was

- | | |
|---|--|
| ☐ Much too little information | ☐ Too much information |
| ☐ Too little information | ☐ Far too much information |
| ☐ About the right amount of information | |

7. Were you satisfied with return of data to you directly by ReveraGen?

- | | |
|---|--|
| ☐ Not at all satisfied | ☐ Mostly satisfied |
| ☐ Mostly unsatisfied | ☐ Very satisfied |
| ☐ Neither satisfied nor unsatisfied | |

8. I would have preferred my child's individual data to be returned by my physician instead of by ReveraGen.

- | | |
|---|---|
| ☐ I strongly agree with this statement. I would have preferred that my physician returned my son's research data. | ☐ I mostly disagree with this statement. |
| ☐ I mostly agree with this statement. | ☐ I completely disagree with this statement. I would prefer to receive my son's data directly from the company. |
| ☐ I'm neutral- either way would be fine. | |

9. I had unanswered questions after receiving the data.

- ☐ Strongly agree ☐ Disagree
- ☐ Agree ☐ Strongly disagree
- ☐ Neither agree nor disagree

10. Who have you told anyone about the results you received from the ReveraGen?
(Choose all that apply)

- ☐ No one ☐ Teachers
- ☐ Family members ☐ Friends
- ☐ Health care providers
- ☐ Other (please specify)

11. Are there other people that you intend to tell about the results you received from ReveraGen? (Choose all that apply)

- ☐ No one ☐ Teachers
- ☐ Family members ☐ Friends
- ☐ Health care providers
- ☐ Other (please specify)

12. I regret having made the decision to participate in this data return study

- ☐ Strongly agree ☐ Disagree
- ☐ Agree ☐ Strongly disagree
- ☐ Neither agree nor disagree

13. If I had to it again, I would participate in this data return study.

☐ Strongly agree

☐ Disagree

☐ Agree

☐ Strongly disagree

☐ Neither agree nor disagree

14. If you regret the decision to receive your son's data or felt that the choice did you harm, can you tell us why? You may skip this question if it does not apply.

15. Do you have any additional concerns, comments, or questions for ReveraGen? You may skip this question if it does not apply to you.

Thank you for participating in the survey!

Best wishes to you and your family.

From the ReveraGen team