Acetazolamide, Baclofen, and Perampanel

Please read the following before completing this survey.

This survey is being conducted for the purpose of research. You may have already completed a survey for this study that we sent out previously. However, we'd like to collect additional information about the use of three medications and would like you to consider participating in this study again.

This survey is being done to gather additional information about three medications (acetazolamide, baclofen, and perampanel) that can be used by individuals with glucose transporter type 1 deficiency (G1D). You are invited to complete this survey because you are an adult (age 18 or older) diagnosed with G1D, you are the parent of a child with G1D, you have been seen in clinic by Dr. Pascual, or you have been approached to be in a research study for G1D with Dr. Pascual at UTSW.

Participation in this survey is completely voluntary. If you choose not to participate in this survey, the decision will not affect your treatment in any way. If you agree to take part in this survey, there are no direct benefits to you. We hope the information learned from this study will benefit others with G1D in the future. Information gained from this research could lead to better care and treatment. You will not be paid for completing this survey.

If you have questions about this study or have questions about other research that our team conducts, please send a separate email to:

Rare.Diseases@utsouthwestern.edu.

By completing and submitting this survey, you agree to participate in this research. To submit the survey, type in your responses to the questions below, save this file, and attach the file to an email to

Rare.Diseases@utsouthwestern.edu.

Thank you for your participation in this survey.

Please read the study Information Sheet provided before starting the survey.

|  |
| --- |
| For all questions, please provide answers about the use of these medications by the person in  |
| your family with G1D.**If the questions don’t apply to you, leave the question blank or respond with “N/A”.**  |
|  |
|  **Acetazolamide - Brand Name Diamox**  |

Has he/she ever taken acetazolamide? 🞎 Yes

🞎 No

What was the daily dose of acetazolamide that he/she took?

Please provide any dosages that you can recall (for example, starting dose, maximum dose, ending dose).

How long did he/she take acetazolamide?

Why did he/she start taking acetazolamide?

What symptoms do you think that taking acetazolamide helped with?

When he/she started taking acetazolamide, how effective was it? 🞎 Extremely helpful

 🞎 Very helpful

🞎 Somewhat helpful

🞎 Slightly helpful

🞎 Not at all helpful

Describe any side effects that he/she's had while taking acetazolamide:

Does he/she currently take acetazolamide? 🞎 Yes

🞎 No

Why did he/she stop taking acetazolamide? 🞎 Side effects

 🞎 Wasn't helpful

Check all that apply.

 🞎 Too many medications to manage

 🞎 Other

Please describe any other reasons why he/she stopped taking acetazolamide:

What's the daily dose of acetazolamide that he/she's currently taking?

How effective is acetazolamide right now? 🞎 Extremely helpful

 🞎 Very helpful

🞎 Somewhat helpful

🞎 Slightly helpful

🞎 Not at all helpful

**Baclofen - Brand Name Lioresal**

Has he/she ever taken baclofen? 🞎 Yes

🞎 No

What was the daily dose of baclofen that he/she took?

Please provide any dosages that you can recall (for example, starting dose, maximum dose, ending dose).

How long did he/she take baclofen?

Why did he/she start taking baclofen?

What symptoms do you think that taking baclofen helped with?

When he/she started taking baclofen, how effective was it?

 🞎 Extremely helpful

 🞎 Very helpful

🞎 Somewhat helpful

🞎 Slightly helpful

🞎 Not at all helpful

Describe any side effects that he/she's had while taking baclofen:

Does he/she currently take baclofen? 🞎 Yes

🞎 No

Why did he/she stop taking baclofen? 🞎 Side effects

 🞎 Wasn't helpful

Check all that apply.

 🞎 Too many medications to manage

 🞎 Other

Please describe any other reasons why he/she stopped taking baclofen:

What's the daily dose of baclofen that he/she's currently taking?

How effective is baclofen right now? 🞎 Extremely helpful

 🞎 Very helpful

🞎 Somewhat helpful

🞎 Slightly helpful

🞎 Not at all helpful

**Perampanel - Brand Name Fycompa**

Has he/she ever taken perampanel? 🞎 Yes

🞎 No

What was the daily dose of perampanel that he/she took?

Please provide any dosages that you can recall (for example, starting dose, maximum dose, ending dose).

How long did he/she take perampanel?

Why did he/she start taking perampanel?

What symptoms do you think that taking perampanel helped with?

When he/she started taking perampanel, how effective was it?

 🞎 Extremely helpful

 🞎 Very helpful

🞎 Somewhat helpful

🞎 Slightly helpful

🞎 Not at all helpful

Describe any side effects that he/she's had while taking perampanel:

Does he/she currently take perampanel? 🞎 Yes

🞎 No

Why did he/she stop taking perampanel? 🞎 Side effects

 🞎 Wasn't helpful

Check all that apply.

 🞎 Too many medications to manage

 🞎 Other

Please describe any other reasons why he/she stopped taking perampanel:

What's the daily dose of perampanel that he/she's currently taking?

How effective is perampanel right now? 🞎 Extremely helpful

 🞎 Very helpful

🞎 Somewhat helpful

🞎 Slightly helpful

🞎 Not at all helpful