

**From:** Fridovich-Keil, Judith [jfridov@emory.edu]  
**Sent:** Monday, April 08, 2013 3:57 PM  
**To:** Undisclosed recipients:  
**Subject:** Gastrointestinal health in galactosemia -- follow-up

Dear Wonderful Volunteers:

Please forgive the form letter nature of this email; I have many dozens of emails to send out today for this study and am trying to be as efficient as possible.

I am writing to thank you again for recently completing our GI Health in Galactosemia survey. The responses received so far convince us that GI health is indeed an area of outcome in galactosemia that requires more attention.

I am also writing to ask for your continued help with this project. Specifically, we need help in two areas:

First, from the initial survey responses and follow-up emails we received from many of you we realized there were two questions we should have included in the original survey but did not.

These are:

1. Has the volunteer been diagnosed with exocrine pancreatic insufficiency (EPI)?
2. Has the volunteer received any other GI-related diagnoses not listed in the original survey?

So, could each of you who completed the first rendition of the survey for yourself or for a member of your household please respond to this email and tell me, for each person you completed the survey for, the responses to these two questions?

Thank you so much!

Second, I am asking for your help recruiting more respondents --- both respondents who have galactosemia and respondents who do not have galactosemia --- for this survey. We especially need more adult respondents so if you or other adults in your household who have not yet completed the survey could please fill out the survey that would be wonderful. We are hoping to recruit at least several hundred additional respondents, both children and adults, both with and without classic galactosemia, so please help us get the word out to anyone you think might be willing to help out. Thank you!

Here is the link for people to click to find the online consent form and updated survey:

<http://survey.emory.edu/fs.aspx?surveyid=2b5135cbaa84851a6b5ca0f354bb22e>

Please let me know if you have any questions or concerns. Thank you again for all your help!

Judy

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## **Bense Family**

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**From:** Fridovich-Keil, Judith [jfridov@emory.edu]  
**Sent:** Tuesday, April 30, 2013 10:36 AM  
**To:** bense@rea-alp.com  
**Subject:** Re: galactosemia research

Thanks so much, Barb.

It would be great if you could please just tell the families that we are still very much in need of more volunteers of all ages -- boys and girls, children and adults, those experiencing great outcomes and those experiencing complications -- and that while we have a variety of different aspects of the study ongoing (e.g. studies of growth and development, ovarian function, scholastic outcome, gastrointestinal health, relationship between diet and outcome, etc.) every volunteer is welcome to participate or not participate in any aspects of the study that are presented to them ...

So ... if any of the families who come to your meeting are interested in learning more about our studies and possibly getting involved please encourage them to contact me directly at [jfridov@emory.edu](mailto:jfridov@emory.edu) or 404-727-3924 and I will be more than happy to speak with them

Thank you again ... I hope you have a great meeting!

Judy

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