



May 11, 2020

Dear Member of the GACI Global Community,

As an organization committed to supporting patients and families with GACI and ARHR2, GACI Global is writing to bring your attention to research currently being done in GACI and ARHR2.

GACI Global is a nonprofit organization whose mission is to connect families affected by Generalized Arterial Calcification of Infancy or Hypophosphatemic Rickets caused by ENPP1 or ABCC6 deficiencies to each other and to the medical community. The organization strives to provide current educational resources and supports ongoing research.

GACI Global is partnering with Inozyme Pharma to learn more from families impacted by ENPP1 deficiency or acute ABCC6 deficiency regarding disease burden and impact of these diseases on your lives. We are reaching out to request that you consider participating.

To be eligible:

- Participant must be a person, or parent/caregiver of a person, with ENPP1 deficiency (GACI or ARHR2).
- Participant must be a person, or parent/caregiver of a person, with acute infantile form of ABCC6 deficiency or ENPP1 deficiency (GACI or ARHR2). Please note, if your child passed away, we welcome your participation.
- Participant must be able to assent or consent to enter into the study.

You must also:

- Provide confirmation of disease (e.g. any form that ties you/your child's name to the diagnosis such as a school note, copy of a chart note or other document).
- Have the ability to participate in the RSVP and interview in English, German, or French irrespective of country of residence and that you can read and write in English, German, or French, and can sign an informed consent.
- Have access to a computer and internet browser prior to the start of the interview.
- Be willing to participate in a 40 minute telephone interview between now and July 31, 2020.

Your involvement would consist of filling out an RSVP survey, providing a document that shows proof of disease, and participation in a 40 minute telephone interview between now and July 31, 2020, which can be conducted in English, German, or French. We have enlisted staff at Engage Health to conduct the interviews for this study. For your time, you will be paid a \$100 honorarium; you may choose to have it paid by check in US dollars OR in the form of an amazon.com e-gift card.

Directors:

Liz Molloy, Christine O'Brien,
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GACI Global is a registered 501(c)(3) nonprofit organization

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There is no preparation required for you to participate. If you would like to participate in the research interviews, please:

- Click [here](#) to RSVP with dates and times that you are available. Please note that times outside of standard business hours are available.
- At the screen, please check the box that says "Check if you have no code" to proceed to the RSVP.
- If you are unable to access the RSVP from the link above, please copy and paste the following URL into your browser bar to access the RSVP:

<https://www.engagehealth.com/survey/TakeSurvey.aspx?PageNumber=1&SurveyID=8252n62#>

If you would like to forward this invitation to other families who speak English, German or French, who are impacted by GACI or ARHR2, please do so.

Interviews will be conducted soon, please respond right away if you would like to participate.

Thank you for your interest,

Liz Molloy and Christine O'Brien
Co-Presidents
GACI Global