

Dear Patient,

**We are writing to let you know about an X-linked hypophosphataemia (XLH) research project which we would like to include your medical information in.** We want to reassure you that you have the right to opt out of being part of this research. Whatever you choose, your medical records remain private and will only be accessed by your care team.

As someone who recently received the medicine burosumab as part of an Early Access Programme for people living with XLH your medical information could help us better understand how this medicine works and improves care for those with XLH in the future.

**Participating in the research is voluntary, and if you are happy to take part no action is required.** Your care team will share relevant and anonymous medical information from your records, during the time you were treated with burosumab, with the research team. This information will help produce a study report about how the treatment works and how it is tolerated in a real-world setting. Fewer than 150 people living with XLH participated in the Early Access Program, so your medical information is extremely valuable to this project. Once the research is complete, we will share the study findings with you.

**We want you to know that you can opt out of being part of this research project.** If you choose not to take part, it won't impact your clinical care in any way.

If you have any questions or concerns about the research project, please speak to your care team and ensure all your questions are answered before making an informed decision. You may wish to discuss this research project with your family or friends.

**If you would like to opt out, inform ADD NAME verbally and/or in writing** using the form below, your care team will then ensure your records are not used in this study.

**If you are happy for anonymised data from your records to be included,** no action is required.

Thank you for considering this request, we appreciate your time and willingness to help with this important XLH research.

Yours sincerely,

**ADD NAME**

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IF YOU WOULD LIKE TO OPT OUT, PLEASE COMPLETE THIS SLIP AND RETURN IT TO YOUR DOCTOR OR CLINIC NURSE

Dear Doctor,

I **do not** want my medical information to be shared for this XLH research project.

Name\_\_\_\_\_