



UPDATE APRIL 2015

## NEWBORN CLINICAL TRIAL OF EDI200

**The XLHED Newborn Clinical Trial of ED2100 continues to enrol new participants!**

As of January we began enrolment into a third group or cohort in the study. This cohort will receive a higher dose of EDI200 than the previous two. For more information about the third cohort please refer to the previous announcement on the Edimer website.

To date **10 newborns** have received the full doses of EDI200 under the clinical trial, the last of which was in **Cardiff, UK**. We continue to gather data from the participants in the trial. This data will then be collectively reviewed before any results can be reported. Until we are able to share more specific data and results, we are able to report that all of the babies continue to do well.

*We remain grateful to the families who have participated in the trial, as well as those who have considered participating. This clinical trial represents a significant milestone for the Ectodermal Dysplasias community and we are excited to be a part of it.*

## XLHED NATURAL HISTORY STUDY

In addition to the Newborn Clinical Trial, **the XLHED Natural History Study is open and enrolling new participants.** *Boys and girls* affected by XLHED, who are under the age of 3 years old are eligible to participate. The Natural History Study helps us understand how XLHED may progress in those who receive standard medical care for the condition. The data from the natural history study will be compared with the data from the babies who received EDI200. Children enrolled in the Natural History Study *will not* receive EDI200.

## WAYS TO BE INVOLVED

*It is important for the community to know that we are still enrolling newborns and will continue enrolling into the natural history study!* We need everyone's help to make sure that all families who know or suspect they are affected by XLHED and are welcoming a new baby are aware that this clinical trial may be an option for them to consider. We encourage everyone to continue to spread the word to your family, friends and healthcare providers about the different way they can participate if they would like.

**Ways to be involved and help spread the word:**

- The XLHED Network to receive regular emails and updates
- Follow the XLHED Network on Facebook and share updates

- Watch and share the Family Experience videos (available with French, Spanish, Italian and German subtitles!)
- Understand your family history of ectodermal dysplasia and share information about the clinical trial with extended family

**If you have any questions, please do not hesitate to contact us – we are here to help!**

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