

X-Linked Hypohidrotic Ectodermal Dysplasia and EDI200 Trial to Cure

(Spring 2017)

In our last newsletter, we wrote about the twins who had been treated with EDI200 by injecting it into the mother's amniotic fluid prior to birth. We are excited to say that the twins sweat glands appeared to develop normally and there are an impressive number of tooth buds, although it is too early to know how many teeth will develop, but the number of tooth buds is encouraging.

Our Next Steps

Two things must happen next:

- As support organisations the ED community Leaders have been put under pressure to find funding to support the families who would like to take part in the trials, by funding their travel and accommodation expenses.
- We also need to continue to follow the babies in the initial Newborn XLHED Clinical Trial as well as those treated in utero to understand the long-term effects of this initial treatment.
- We need to continue the Natural History Study. This study enrolled boys and girls with XLHED during infancy and they will be followed until they are five years old. This important study will help us better understand the natural history of XLHED so we can improve care for the people it affects. Because it's rare, we still have many unanswered questions about XLHED. Also, the study participants will serve as a control group for the therapeutic trial for EDI200.
- The ED support organisations play a very big part in the trials – without us the Researchers would not have access to so many families.



Once successful in XLHED boys the research will move to treating girls and from there onto treating the different syndromes of Ectodermal Dysplasia.

If you would like to join the Natural History Study please contact diana@edsociety.co.uk – we need as many boys and girls as possible.

Whilst the Researchers are seeking funding from large organisations and institutions, we need to assist with the smaller expenses such as travel and accommodation. If you feel this project worthwhile please fundraise or send your donations to us.

Supporting a normal lifestyle

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