This presentation is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $600,000 with 0 percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.
Disorder name: X-Linked Adrenoleukodystrophy
Acronym: X-ALD

- What is X-ALD?
- What causes X-ALD?
- How is X-ALD inherited?
- What are the symptoms of X-ALD in males?
- What is the treatment for X-ALD in males?
- What happens when X-ALD is treated?
- Is genetic testing available?
- What other testing is available?
- Can you test during pregnancy?
- Can other members of the family have X-ALD or be carriers?
- Can other family members be tested?
- How many people have X-ALD?
- Does X-ALD happen more often in a certain ethnic group?
- Does X-ALD go by any other names?
- Where can I find more information?

This fact sheet has general information about X-Linked Adrenoleukodystrophy (X-ALD) in males. Every child is different and some of this information may not apply to your child specifically. Certain treatments may be recommended for some children but not others. If you have specific questions about X-ALD and available treatments, you should contact your doctor.

If your newborn has had a positive screen for X-ALD after newborn screening, it does not yet mean that he definitely has X-ALD. There are usually other medical tests (for example, blood tests) that need to be done to confirm whether your baby actually has X-ALD.
Emerging Preference for Video Education

Parents told us they prefer to watch videos rather than read fact sheets.

68% of U.S. adults use YouTube*.

94% of 13-24 year olds use YouTube*.

*March 1, 2018 Pew Research Center Study
Things to Consider

- Decide which fact sheets to convert first.
- How to turn text into visual images?
- How much information to include?
- Who to do voiceover?
- Find someone to do it.
Sample from Video
Review Comments

39 reviews since mid-March 2019
The vast majority stated:

- Covered what X-ALD is, treatment, management, and how it is inherited
- Covered the right amount of information
Review Comments

Would use video to:

- Share with family and friends
- Share with healthcare providers
- Share with school when appropriate
**Review Comments**

- Music in background was difficult for hard of hearing.
- Slow down the voiceover since technical terms used.
- Can’t stand the voice for the voiceover. S’s and X’s were annoying.
- Shocking to see child in wheelchair.
- Mixed race confused parent that this only occurs in certain races.
- Birthdate on screening card says 1/1/2018 which is not a newborn.
- Boy in video wasn’t smiling.
Next Steps

- Use multiple voices and dialects.
- Use multiple combinations of couples.
Next Steps

- Try removing the music.
- Slow down the voiceover.
- Add slide to show multiple ethnicities.
- Change date on screening card.
- Continue parent testing.
Mahalo

Lila Aiyar, M.S., C.G.C.
WSRGN

Jessica Tarnowski, M.S., C.G.C.
CA, HI, WA Family to Family
Health Information Centers

All the parents who did reviews
Questions?

Sylvia Mann, M.S., C.G.C.
sylvia@hawaiigenetics.org