



7

resources:
tools and assets at your disposal

“ I always bring a one-sheet of ‘What is ALD’ with basic facts. As you can imagine, all of the legislators are busy and aren’t going to become experts in this disease. We need to provide them information in an easily accessible way. If they have questions, they have something to go back to. ”

—ELISA SEEGER
ADVOCATE IN NEW YORK

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Adrenoleukodystrophy and leukodystrophy patient advocacy organizations*

- [AIALD](#)
- [ALD Alliance](#)
- [ALD Connect](#)
- [Brian's Hope](#)
- [Calliope Joy Foundation](#)
- [Ethan Zakes Foundation](#)
- [Fight ALD](#)
- [Global Leukodystrophy Initiative](#)
- [Leukodystrophy Resource and Research Organization](#)
- [Hunter's Hope](#)
- [United Leukodystrophy Foundation](#)

Newborn screening (NBS) and rare disease advocacy organizations

- [AISMME](#)
- [Baby's First Test](#)
- [Everylife Foundation](#)
- [EURORDIS](#)
- [Global Genes](#)
- [IPOPI](#)
- [National Organization for Rare Disorders](#)
- [UNIAMO](#)

General advocacy resources

[A guide to public speaking](#)

NBS resources

[What is NBS? Animated video for parents](#)

[The role of laboratories in NBS](#)

[Example of NBS blood specimen collection](#)

[Example of economic impact of NBS for ALD](#)

[Advocacy for the community NBS](#)

[Importance of NBS](#)

Rare disease resources

[Using storytelling to raise awareness for your rare disease](#)

[How to promote your rare disease story through social media](#)

[Contact a representative \(US\)](#)

Note that this is only a sample listing of resources that may be helpful to you in your advocacy efforts.



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importance of NBS

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NBS and ALD

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what is advocacy?

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NBS today

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NBS panels: US, UK, & EU

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getting involved

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FAQ

