

1

the importance of NBS for ALD:

a call to action from like-minded advocates around the world



“ **Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.** ”

- MARGARET MEAD

CULTURAL ANTHROPOLOGIST

1

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Newborn screening (NBS) for adrenoleukodystrophy (ALD) means possibly saving children's lives.

It is critical, primarily for boys, who are most severely affected by the condition, but also to a lesser extent for girls, for extended-family screening and future planning. As a rare, X-linked metabolic disease, ALD can lead to adrenal problems such as adrenal insufficiency and potentially more serious complications if not detected early and managed. Early diagnosis through NBS enables the parents of young boys to know, from a very early point in the child's life, that their child must be monitored for progression to a life-threatening form of the disease—cerebral ALD. **By finding this information out while a child is still a baby, doctors can help each family plan for the future.**

They can also realize that **there is hope**. NBS for ALD provides access to a 'window of opportunity' and allows for the timely commencement of available therapies. Early detection of cerebral ALD may allow doctors to treat the disease in time to save lives.

The following quotes are from advocates and parents who are advocating for the inclusion of ALD as part of NBS panels. **Their voices explain firsthand how important it is to screen newborns for ALD.**

“

There are a number of ways you can use your voice to support the ALD community... We need to drive the message home that this doesn't just happen to one boy. This disease can be stopped, and the cost of screening is minimal.”

– ELISA SEEGER / advocate in New York

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To advocate for NBS, you don't need to start an organization or a foundation, you can be an individual or a family who is just passionate about this cause... As horrific and difficult as diagnosis may be for a family, just knowing gives them the benefit of time, to be able to monitor the disease and be in a position where they can take necessary medical intervention at the appropriate time. That in my mind is the key. [NBS] will save lives. I think it already is.”

– BRAD ZAKES / advocate in Washington

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I advocate by setting the goal to have NBS implemented and then ensuring that happens by establishing and changing systems...the health system, political system, and social system. I talk to geneticists. I talk to members of Parliament. I am always making a case for inclusion of NBS. I do anything and everything that I can at every level to raise awareness.”

– BOB WYBORN / advocate in Australia



1

importance of NBS

2

NBS and ALD

3

what is advocacy?

4

NBS today

5

NBS panels: US, UK, & EU

6

getting involved

7

resources

8

FAQ

