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what is advocacy?

making a real difference in people's lives

**“ 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. ”**

**-JANIS SHERWOOD**  
ADVOCATE IN CALIFORNIA





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The World Health Organization (WHO) defines advocacy as the process of influencing people to create change.

**Advocacy** may be broadly defined as a strategic series of actions that accomplish the following goals and is a fundamental concept for affecting governmental actions:

- **Speaking in favor of a particular cause**
- **Influencing and arguing for a change in public policy and public opinion**
- **Prompting a transformation**

Regardless how or where they start, all types of advocacy can be broken down into three different concepts: mission, action, and change. Whether you have an entire organization behind you or you are simply an individual, the purpose behind advocacy is to have a mission, take action, and engender change.

### 1 MISSION

Advocacy is an active process that starts with a common mission. Advocacy in all forms seeks to ensure that people in a society are able to raise their voices, defend and safeguard their rights, and have their views genuinely considered when decisions are being made about their lives.



**Example: Your mission may be to see newborn screening for adrenoleukodystrophy implemented in your state or country.**

### 2 ACTION

Taking action for advocacy involves taking part in a broad range of activities that include, but are not limited to, raising awareness through public education, campaign tactics, experience-based events, social media, researching, and lobbying. In a time when the network of digital platforms continues to expand, there are more ways than ever before to get involved and make your voice heard. Many families turn to social media first to begin their advocacy efforts.



### PUBLIC SPEAKING

Language is one of the most powerful tools that we have, allowing us to create new connections, channel empathy, and influence the actions and decisions of political leaders who may not be familiar with how their decisions affect their constituents' lives. Advocacy groups and organizations often enhance their voice through public speaking and by generating an online presence. By doing so, they are able to convey their message and, ultimately, create a positive impact.

Public speaking may sound daunting, but there are tools and tips to help you along the way. Remember, practice makes perfect.



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### CAMPAIGNS/EVENTS

Spreading a message through the use of campaign tactics, such as organizing a meeting in your neighborhood, is another way to generate traction and create a movement. Local grassroots events are a great way for advocacy groups to network and reach individuals on a larger scale to help make a difference.



### LOBBYING

Lobbying is a method of advocacy that occurs when an individual or a private interest group works to influence legislation at the local, regional, or national level.

Rules and regulations around lobbying requirements and registrations may differ from state to state and country to country.



### DEVELOP CHAMPIONS WITHIN POLICY MAKER CIRCLES

Advocacy is usually first approached by generating public awareness about a particular cause or issue. Once public awareness regarding the issue has gained traction, policy makers may then evaluate and potentially decide to champion the need to take action.



One way to raise public awareness about a particular cause is by leveraging social media platforms. See [Take Your Voice on Social](#)

## 3 CHANGE

Change doesn't happen overnight. It takes diligence, commitment, and a relentless passion to get a message out into the world, connect others through a single vision, and keep them engaged long enough to drive transformation. It may not be easy, but with a goal in mind and a plan in place, advocacy can have an impact on the lives of many and, ultimately, be the force for change. It's only when action is taken for a particular cause that its end goal becomes attainable.



Change can seem like a slow process, but our collective efforts are worth it. Since the 1960s, patient advocacy groups in the United States have been instrumental in efforts to mandate state testing of newborns. However, once the condition is included, all newborns who undergo newborn screening will be screened for that condition locally. This is a good indication for advocates around the world that change is really possible at the local level.



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## Advocacy for NBS

Advocacy for newborn screening (NBS) has been a global concern and a continuous law-changing effort worldwide. Although some progress has been made, **NBS programs around the world still require improvements, and most still do not include adrenoleukodystrophy (ALD).** As countries decide which diseases to add to their programs, advocates around the world still play an incredibly important role in raising awareness about the need for expanded NBS.

“ I am someone who 10 years ago found out my son had ALD and was waiting for the other shoe to drop. I should buy a lottery ticket every day; I'm this lucky that we've had 10 years of good health and knowing and watching science progress... There's not one friend or colleague I have that has lost a child or family member to ALD who did not wish they knew one day sooner. It's frustrating that NBS is not available everywhere. It's always worth knowing.”

– KATHLEEN O'SULLIVAN FORTIN /  
advocate in Massachusetts

## Who advocates for NBS and how does it become actionable?

Adding a disorder to the NBS panel is done through a collaborative process that may involve relevant stakeholders and influencers such as genetic specialists, public institutions, health agencies, NBS laboratories, healthcare providers, patients' associations, and policy makers. Here is where your story and your voice can make an impact. As it relates to NBS advocacy, here are some stakeholders that you may want to reach, engage, and influence to make your case for NBS:

### • General Stakeholders

- Families with ALD in your state or country
- Advocates for NBS for ALD and other rare diseases

### • Influencers

- Media
- Patient/community advocates
- Healthcare professionals (public health officials, researchers, health agencies, etc)

### • Specific NBS decision-makers

- Primary audience: Legislators/regulators, policy makers, Commissioner of Health
- Secondary audience: Medical professionals, laboratories



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