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what YOU can do:  
how to get involved

“The time to act is now. A validated and accurate screening test for adrenoleukodystrophy is available. We highly recommend adding newborn screening for ALD to the current state panel. Let’s do what we can to help young boys avoid suffering the devastating effects of this deadly disease.”

-BRAD ZAKES

ADVOCATE IN WASHINGTON





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### Importance of framing

Every story has a beginning, middle, and end. Each piece of the message matters. To ensure that your story has the most impact for your audience, you'll want to frame it with a strong beginning that captures attention and a memorable ending that calls the listener to action.

Start with a strong statement that lets your audience know you recognize that your voice matters. Have confidence in what you have to share and the importance of your message.

Consider beginning with a statement of the personal impact of newborn screening (NBS), or lack thereof, on you, your family, or someone else you know who is affected by adrenoleukodystrophy (ALD). Remember, **you are the expert of your own story.**



#### Examples of strong initial statements from the parents and caregivers of children with ALD:

**Example:** *The day my son was diagnosed with ALD was too late; I was aware that he should have been screened for this. He could have been diagnosed earlier. We could still have our son with us today.*

**Example:** *We entered the hospital with a little boy full of energy and personality, and we left the hospital with a little warrior who couldn't walk and couldn't communicate with us. We were all just devastated. We needed to learn a new life. NBS could have prevented this outcome for our family.*

**Example from Brad Zakes:** *We are like so many other stories. We just thought our son had attention deficit disorder or that he was just kind of a unique little kid. But it wasn't until his symptoms got to the point where we knew there was something really serious going on that it was really too late. As horrific and difficult a 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. It will save lives. I think it already has.*

**Example:** *ALD doesn't just happen to just 1 boy. This is not an isolated event. The disease affects 1 in 21,000 males born each year. The devastation of this disease can be stopped and the cost to do so is minimal.*



**End with a memorable action that gives your audience a way to get involved. The action you end with may encourage a stakeholder to become an advocate, inspire an influencer to share your message, or activate a decision-maker to promote NBS for ALD.**

**Example:** *Will you help me to share my story and bring awareness of ALD and the importance of NBS to a larger community?*

**Example:** *How can we work together to ensure families receive early diagnosis of ALD and can properly monitor for disease progression before it's too late?*

**Note:** *The examples shown above are not real stories, just ways to illustrate the importance of framing.*



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### ACTIVITY - DEVELOPING YOUR STORY

Try responding to each of the questions below in 1 or 2 succinct sentences. Then organize your responses into an order that makes sense for your overall message. You'll find your story beginning to develop. Don't forget to frame your story with a strong beginning and a memorable ending. And be sure to sprinkle in some facts about adrenoleukodystrophy (ALD) and newborn screening (NBS) to add to your message.

What is ALD?

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How has ALD affected you and your family's life?

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Why is early detection of ALD critical to you? To all those diagnosed with ALD?

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How did NBS play a role in your family member's diagnosis, if at all?

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Why do you think NBS is important and how has it affected your life?

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What action do you want to leave your audience with?

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**Example from Brad Zakes:** *In May 2011, Ethan passed away at the age of 10, just 5 months after being diagnosed with cerebral ALD. ALD is a genetically acquired degenerative neurological disorder that causes damage to the nerve cells of the brain and the adrenal glands. Approximately 1 in 21,000 boys are born with the condition each year. Unless a family history of ALD is known, the disease is rarely detected at birth. As a result, most young boys appear to be completely healthy during their early childhood and remain undiagnosed until later in life (at approximately 4 to 10 years of age), when they start to show initial symptoms—frequently too late to stop the progression of this devastating disease. As a result, death is an unfortunately common outcome for many young boys. NBS provides the opportunity to detect the disease shortly after birth. By simply detecting the disease early in life, boys diagnosed with ALD can be monitored for cerebral progression and receive treatment to better their chances of living a normal, healthy life. A highly reliable and accurate screening method utilizing dried blood spots from standard neonatal screening cards has been developed to diagnose ALD when it matters, early.*

Remember, it is likely that **most of the individuals** with whom you share your story will **have never heard of ALD**. Others may be unaware of NBS. This is your opportunity to educate. **You are the expert.** As you share your personal story with them, don't forget to answer the basics by defining the condition, the incidence, and the potentially devastating impact. Consider visiting [NavigatingALD](#), [ALD Connect](#), [ALD Alliance](#), or other patient advocacy organizations and resources for information and facts for you to include in your message.



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### Share your message

Now that you have crafted your story, it's time to identify your audience and begin to share your message, ideally by working together with other advocates.

“People don't realize how powerful they are. They have power directly with key decision-makers. They have power through sharing their story.”

– BOB WYBORN / advocate in Australia

### Who will you share your story with?

As an advocate, you'll share your story with a variety of audiences as you work to seek newborn screening (NBS) for adrenoleukodystrophy (ALD) in your state or country. As you read earlier in the “What is Advocacy?” section of this tool kit, you will find that your audience typically falls in one of three categories: stakeholder, influencer, or decision-maker.

**STAKEHOLDER** — Your stakeholders are those who are impacted by NBS for ALD. This includes the families and individuals with ALD living in your state or country. Sharing your story with stakeholders can be a great way to identify fellow advocates! By sharing your story, you can inspire and invite others in the community to craft their own story and raise their voice on the importance of NBS for ALD with you.

**INFLUENCER** — Your influencers are those who can make decisions or have an impact on those empowered to make decisions related to NBS. The media is a perfect example of an influencer!

**DECISION-MAKER** — Your decision-makers should be your primary audience. These are the individuals and entities who directly decide on, and impact, the adoption of NBS for ALD in your area.

Remember, it's okay to not know the answer to a question. In fact, it's normal for you to be asked a question you may not be able to answer. In those instances, be honest. Let your audience know that you appreciate their question and are happy to connect back with them at a future time with more information. Or connect with a patient advocacy organization who may be able to offer a clear response for you to provide.

“You can work at all levels at the same time. You can meet with people you may perceive as daunting because of their position, although they're just normal people. Or you can meet with small mom and pop groups. And one conversation informs another. You learn as you go.”

– BOB WYBORN / advocate in Australia



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### ALD and NBS facts and figures:

- Newborn screening (NBS) is a process in which **newborns are tested for a select group of rare diseases** to help prevent symptoms and allow for early treatment
- Adrenoleukodystrophy (ALD) is a rare, X-linked disease that occurs in about 1 in 21,000 males and about 1 in 17,000 newborns in the total population
- ALD is caused by an underlying genetic mutation in the *ABCD1* gene and affects the body's ability to create the protein that helps in the process of breaking down very long-chain fatty acids (VLCFAs)
- A buildup of VLCFAs can cause adrenal problems and can potentially lead to brain damage. **ALD that progresses** to affect the brain is referred to as **cerebral ALD**
- **About 40% of boys with ALD will develop cerebral ALD**, which leads to irreparable, progressive demyelination and neurodegeneration resulting in disabilities such as an inability to speak or respond, blindness, or even death

### Diagnosis and treatment

- **Early diagnosis of ALD** and signs of cerebral demyelination and neurological symptoms can save lives. Once ALD is diagnosed, it is recommended that affected boys be monitored regularly with a brain MRI to detect cerebral involvement as soon as it develops, and treatment can be considered
- If treated early, **stem cell transplant can dramatically improve the outcomes** of affected boys

- **If treatment is delayed** until the condition is apparent clinically, **outcomes are shown to be worse**, frequently leading to death
- **NBS for ALD is the earliest form of detection** and is an opportunity for families to engage in monitoring for potential progression to cerebral ALD

### NBS for ALD

- **NBS for ALD saves lives**
- Without NBS, early lifesaving therapy has been available only to those diagnosed because of diagnosis through known family history
- The **ALD NBS test is accurate and inexpensive**, with an estimated price of about \$5.00-\$11.00 per test in the United States; globally, this cost varies
- The screening method utilizes dried blood spots from standard neonatal screening cards
- The test is performed via high-throughput screening assays using tandem mass spectrometry
- The test has a high level of specificity (low false-positive rate)
- ALD met all of the criteria for inclusion on the United States' national Recommended Uniform Screening Panel and is currently screened for in 18 states as of January 2020



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### Support letter template

When advocating for newborn screening (NBS) of adrenoleukodystrophy (ALD), it may be important to include a letter of support or two from a healthcare provider, institution, or expert from the leukodystrophy community who can verify and bolster your message that NBS for ALD is critical. To the right is a template that you can use to adapt a letter of support with a provider, institution, or leader of your choosing whose voice can help to support your advocacy efforts.



**Request the letter be placed on official letterhead from the healthcare provider, institution, or opinion leader you are working with to adapt the letter. This can offer some clout and additional authority to your overall message.**

**Remember, advocacy organizations may be able to help you to identify someone to sign on to your letter of support.**

You can create your own letter by zooming in on the template below and copying language to help get you started. From there, add your own individual touches to make it feel more personal.

First Name Last Name mm/dd/year  
 Organization, Title  
 Address  
 City, State Zip Code, Country

Dear Mr./Mrs./Ms. Last Name,

I am writing to express strong support for the implementation of newborn screening (NBS) for adrenoleukodystrophy (ALD), an X-linked genetic disorder that occurs in about 1 in 17,000 newborns in the total population. Caused by an underlying genetic mutation in the ABCD1 gene, ALD affects the body's ability to create the protein that helps in the process of breaking down very long-chain fatty acids (VLCFAs). A buildup of VLCFAs can cause adrenal problems and can potentially lead to brain damage in a form known as cerebral ALD. Unfortunately, many boys with ALD go undiagnosed until symptoms of cerebral disease have developed. If cerebral ALD is left untreated, there are severe side effects, including significant disabilities, such as an inability to speak or respond, blindness, or even death.

Hematopoietic stem cell transplantation with related and unrelated donors can prevent progression of the cerebral form of ALD if performed before or soon after the patient has manifested clinical symptoms of the disease. If diagnosed early, MRI may be able to detect the advancement to cerebral disease before clinical symptoms appear and at a time when treatment may be effective. Conversely, if transplantation is performed in symptomatic children, the disease usually progresses and the child either dies or stabilizes in a severely debilitated state.

Most families are unaware of the fact that they are at risk for having a child with ALD until the child becomes symptomatic. Usually it's too late to help at this time. Although subsequent pregnancies or births can be screened, this approach fails to rescue the first child who could have been diagnosed early, and could have had access to a hematopoietic stem cell transplant, but was not.

Another important reason to identify these children with NBS is because some will present with life-threatening problems due to adrenal crises, which arise as adrenal insufficiency develops. In many children this occurs before the onset of neurological symptoms. Given that adrenal crisis is also life-threatening, it is a second compelling reason to screen newborns for ALD.

NBS is an intervention that offers the potential to save the lives of hundreds of children with ALD. Early diagnosis of ALD followed by routine, serial brain MRI screening has the potential to dramatically impact treatment options for affected boys with ALD. The critical aspect in achieving optimal outcomes is detecting the disease before it results in too much damage to the brain. In this circumstance, NBS is an excellent candidate for making a difference in this devastating disorder.

ALD was added to the Recommended Uniform Screening Panel in the United States in 2016, verifying that NBS is the recommended diagnostic option for ALD. With a sensitive, specific, and timely test developed and able to be adapted for mass screening, the overtime and overall cost-effective nature of screening for ALD at birth cannot be argued.

In summary, I highly recommend that <<Insert Decision-Maker>> undertake the task of adding NBS for ALD to the current panel. Please do not hesitate to contact me if you require additional information in support of this request.

Sincerely,  
 <<Insert Signature>>  
 <<Insert Contact Information>>



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“ Advocacy organizations can help a family to connect to others in their state and to find those stories to share and emphasize that message. I encourage families to find the different stories of adrenoleukodystrophy (ALD) to show the diverse outcomes and impact the disease can have on an individual and a family if not diagnosed at birth.”

- ELISA SEEGER / advocate in New York

“ For newborn screening (NBS), social media is a great tool. Local news coverage featuring a family in that area affected by a leukodystrophy is very effective. I think videos can be impactful, as people may not want to read a story, but they can certainly watch one.

As your advocate, whatever medium you’re using, you have to stay close to the heart of why you are advocating. The truth of these stories is tragic and moving and inspiring. I think whatever medium you’re using, always bring it back to the reality that NBS is the difference between life or death for these kids. That’s why you’re advocating.”

- ANNA GRANTHAM / advocate in Alabama

**i** Keep in mind, decision-makers may be interested in your story, but they will need facts and figures to support your overall message and encourage them to make a change with you.

When sharing your story with decision-makers, be prepared to answer specific questions, including:

• **Is there a reliable test to screen for adrenoleukodystrophy (ALD)?**

- Yes. In the United States, and in some other nations, a reliable and accurate screening test for ALD has been developed utilizing dried blood spots from neonatal screening cards. The test has been shown to have a high level of specificity and a low false-positive rate

• **Which US states and countries are screening for ALD?**

- As of September 2020, 17 states and DC have active screening programs for ALD, and the condition has been approved on the Recommended Uniform Screening Panel, validating that:

- There is a specific and sensitive test available to detect ALD
- The health outcomes of ALD are well understood
- There is an available and effective treatment
- Identification of the condition could affect the future reproductive decisions for a family

- ALD is currently screened for in a pilot program in the Netherlands and Germany

• **Is NBS for ALD cost-effective?**

- Yes. Early diagnosis of ALD through newborn screening (NBS) programs lowers care and education costs and improves the chances of patient survival



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## what YOU can do: how to get involved

### Encourage advocacy from others— sharing your message with stakeholders

It's no secret that more voices can expedite and enhance your overall message: **newborn screening (NBS) for adrenoleukodystrophy (ALD) is necessary!**

Consider sharing your story with other ALD families and broader community members to communicate the importance of NBS for ALD and the impact their voices can have with yours.

Reach out to one or more patient advocacy organizations to connect with other families in your area. Invite them to join you in advocating. Advocacy organizations can help you to connect to other advocates or families in your region and assist you in navigating the advocacy process, identifying decision-makers, and sharing your message.



“Connect with the people who have been involved in this community and with advocacy. Talk to them. Ask them questions. Families who have been dealing with this longer are truly some of the greatest resources. I wouldn't be the advocate I am without them. Connect with the community. Don't be afraid to seek help and ask questions just because you feel you may not know enough about the disease or how the process works.”

– FRANI BROUSSARD / advocate in Texas

Section 7 of this tool kit includes a variety of resources, such as patient advocacy organizations you may choose to contact that are active in ALD and NBS.



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## Contact your local media outlets: Sharing your message with reporters/influencers

The media can be a partner to you in sharing your story and the importance of newborn screening (NBS) for adrenoleukodystrophy (ALD). Consider approaching a variety of media outlets, including community newsletters, local newspapers, regional news agencies, etc.

### Parents Lobby States to Expand NBS Test for Rare Brain Disorder

When connecting with media outlets, consider the following questions:

- Who is their audience?
- How wide is their reach?
- How can you gain their attention?

Knowing the answers to these questions will help you to prepare your message and method of contact.

“I pretty much reached out to the major news channels with my story to try to get them interested in raising awareness about ALD and about NBS. My suggestion to others would be to reach out to your local newspaper and television stations and get coverage that way. Let them know your story and the story of NBS.”

– JANIS SHERWOOD / advocate in California

Janis shared her story with local media as she advocated for ALD NBS in California. Here is an article that was printed in the San Diego Union Tribune about her advocacy efforts to raise awareness of ALD, courtesy of the San Diego Union Tribune:

### Janis and Sawyer's story

**i** You might be surprised how connected you and your immediate network may be. Advocate Frani suggests sharing your efforts broadly and talking about them often.

*“I tell everyone I know; sometimes you may not want to talk about it, or it feels like you are burdening someone with what is affecting your life. But the more you share the more you find that people are truly willing to help. Talking to a network is important. People want to help. They want to help you and they want to help your family.”*

When working with the media:

- You can ask to see questions in advance of potential interviews
- You can suggest questions in advance of potential interviews
- You can rule out topics you prefer not to respond to

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### Encourage change through action: Sharing your message with decision-makers

Once you have identified the decision-makers, you will want to prepare information to help them to see the critical importance of newborn screening (NBS) for adrenoleukodystrophy (ALD).



**Change comes from the action of sharing your story; this is Jean Kelley’s message about the importance of advocacy.**

*“The most important thing we did was make an appointment with the Health Committee in Connecticut. I made some fact sheets and took Brian with me and explained to them what ALD is and what Brian’s challenges had been since he was diagnosed and all that he had been through. We shared that there was an opportunity for NBS to identify this disease early and help children to survive without the hardships that Brian had with early detection, monitoring, and treatment.*

*The impressive thing was that Brian sat quietly and listened and moved his eyes to those who were speaking, although he doesn’t see. And he moved his lips to answer questions about things that he liked... just yes or no questions, but he was able to communicate. They could understand that he was convinced that no one should have to live like that. They realized that if they could do something about this disease, they should. The committee approved the bill and efforts started to move forward. I impressed upon them that NBS is money-saving and how expensive is Brian’s schooling and health care, and how fortunate we were to have private insurance, whereas a few other families in the state were dependent on state healthcare.”*



I encourage other advocates to share the power of their experience with ALD, and also to touch upon the money-saving aspect of NBS. It’s the bottom line. It went through appropriations, so they have to see things from that perspective. We invited our representatives to our home, let them in and showed them everything we need to accommodate Brian’s new needs—a lift, a ramp, a specialized bathroom—all of the things that made Brian’s life easier for him and for us.”

– JEAN KELLEY / advocate in Connecticut



**As an advocate, consider using your child’s medical bills as a representation of just how costly diagnosis outside of NBS can be on a family and on a healthcare system.**

Please only contribute personal information that you are comfortable with sharing.



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### Bring a leave behind

Many advocates choose to bring a small package of information such as a leaflet with them when speaking with decision-makers to support their overall message.

This package of information may include:

- **Your story (1 page)**
- **A few images of individuals affected by adrenoleukodystrophy (ALD) (approximately 3 to 5)**
- **Quick facts about ALD and NBS (1 page)**
- **Letter of support (approximately 2 to 3)**
- **Contact information (2 business cards)**

Consider packaging your leave-behind in an open folder to give to a decision-maker. Some offices will not allow materials to be left behind in closed envelopes for security reasons.



You may want to include the contact information for a local Patient Advocacy Organization with expertise in leukodystrophy and/or newborn screening (NBS) within your materials. This will allow individuals another outlet to reach out to with questions. You can start to identify patient advocacy organizations in the resources section of this tool kit.



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. I also bring letters of support from institutions and clinicians and physicians who also advocate that newborn screening is necessary. I then leave these pieces behind with them. If they have questions, they have something to go back to. Telling your story is the most important thing, but then leave those fact sheets behind as a reminder.”

– ELISA SEEGER / advocate in New York

Make an appointment to meet with decision-makers in person or via video. Bring your package of information with you and be prepared to speak with members of their staff before ever having an opportunity to speak with the decision-maker directly.



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### How will you share your story?

With today's technology, you may be contacting stakeholders, influencers, and decision-makers in a variety of ways:



EMAIL



FACE TO FACE



PHONE



MEDIA  
(PRINT,  
DIGITAL,  
TV)



SOCIAL  
MEDIA/ONLINE  
DIGITAL  
PLATFORMS

At times, you may be engaging in cold-calling or cold-emailing by contacting individuals you do not know but who you have identified as a key stakeholder, influencer, or decision-maker in your region. You might identify these individuals by the role that they serve, the area of focus they work in, the causes they have supported previously, or the influence they hold in your community

“You get more ‘no’s’ than you get ‘yeses. Don’t be discouraged. When you get that one ‘yes’ all of the ‘no’s’ disappear. How many kids can that one ‘yes’ save? I always try to stay focused on...if my efforts to raise awareness of adrenoleukodystrophy and newborn screening saves just 1 boy, that’s a life... that’s worth it. Don’t give up. Sometimes it takes multiple attempts before someone will hear you out on what you have to say.”

- JANIS SHERWOOD / advocate in California

“I find people to be receptive to connecting and hearing me out. Advocates should always be proactive, anticipate someone’s questions, and leave the door open for someone to get back to you when they’re ready to learn more... I send a lot of emails and make a lot of phone calls. I often find people through social media.”

- BOB WYBORN / advocate in Australia



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### Tips for cold calling

- In advance of your call, **research** the individual you are calling and note why you have chosen to reach out to them about newborn screening (NBS) for adrenoleukodystrophy (ALD)
- **Open with a strong statement** that shares who you are and why you are calling
- Do not ask “Is now a good time?” It’s always a good time to advocate and educate. **Launch** straight into your purpose
- **Describe ALD** and the critical importance of early diagnosis
- **Let the listener know** that NBS for ALD is already being implemented in some states in the US and that a test for ALD NBS is already available and might only need to be localized
- **Make an ask.** Prior to your call, predetermine what action you want the listener to take at the end of the conversation. You may want to set up a meeting. You may want to get their ‘OK’ to do a news article on your family. You may want to get their ideas for how to raise awareness on social media
- Whatever your ask is, don’t end the call until you’ve **shared an action**
  - Ask for an appointment at a specific time. You want your listener to commit to a meeting so you can share more
  - Ask for the name and number for a colleague who focuses on human interest pieces
  - Ask what additional information they may need to consider advocating with you for NBS for ALD



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### Tips for being an engaging and confident speaker

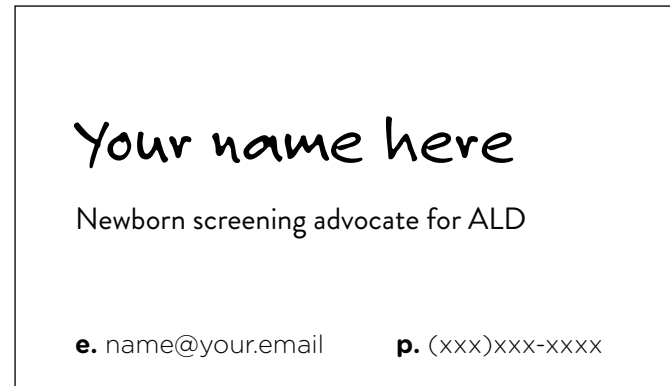
- **BE YOURSELF.** Let your own voice shine through. Don't try to alter who you are or how you communicate to reflect someone else.
- **PRACTICE MAKES PERFECT...** or at least makes you more comfortable! Get comfortable with your story. Practice with friends and family. Or consider filming yourself with a tablet, computer, or smart phone and watching the replay.
- Don't look for perfection, **LOOK FOR IMPACT.**
- **PAY ATTENTION TO YOUR BODY LANGUAGE.** Your body language tells a huge part of your story and often conveys how confident you are in what you're sharing. Although subtle, your body language can speak volumes. Think about standing up straight, making eye contact, and taking deep breaths. Plant your feet and hold your head high.
- **BE COURTEOUS.** We all appreciate being approached with respect, kindness, and a smile. Manners matter and your audience will always remember how you made them feel.
- Remember, no one knows your message and your story better than you. **YOU ARE THE AUTHORITY.** You have permission to speak like it, regardless of your audience.
- **BE RESILIENT.** As an advocate, you may not always receive the response you're looking for. Your audience will not always connect with you. And you will not always make the impact you hope for. The key is to keep a positive attitude and to continue to push forward and advocate.

### Leave your contact information behind

Be sure to leave your contact information behind. You'll want them to remember your name and how to contact you should they have more questions or want to learn more.

#### Activity: Create YOUR advocate business card

You can create your own by using the template below for reference:



### Follow-up

No matter how well your audience receives your message in the moment, sometimes they can forget to respond and forget to engage. Don't be afraid to send a gentle reminder after a few days. A phone call or email are great forms of follow-up.



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### Take your voice on social media

Social media can be a powerful tool for advocacy efforts and allow you to educate and inspire a broad audience. There are more than 3 billion Internet users around the world, with more than 2 billion people having a social media account. With so many different social media platforms at our fingertips, it might feel overwhelming to decide which platform to use and how to best share your message. There is no correct answer, but Twitter is a platform where key decision-makers tend to engage more actively.



Each September is newborn screening (NBS) Awareness Month. Help to raise awareness of the importance of NBS through hashtags, such as:

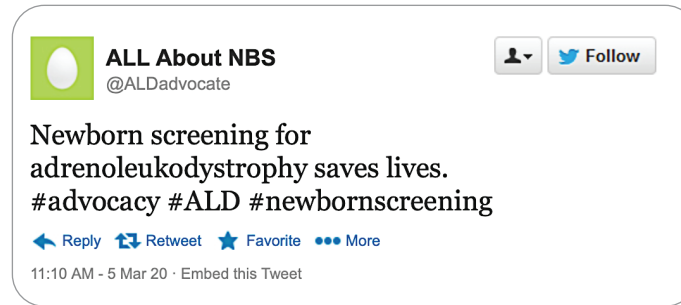
- #NewbornScreeningAwareness #NBS
- #NewbornScreeningMonth #newborntesting
- #NBSMatters #NBSSavesLives

### Twitter

Members of Congress and Parliament, legislative staffers, and policy makers tend to have an active presence on Twitter. As a platform, Twitter allows users to have real-time conversations. Consider using hashtags such as **#ALD**, **#adrenoleukodystrophy**, **#raredisease**, **#newbornscreening**, **#advocacy**, and **#myvoice** to broaden your message's reach.

**Remember:** Keep your social message short and sweet, 280 characters or less. Your tweet should galvanize your audience to action and/or heightened awareness. Remember that tweets with photos are more likely to be shared and will help spread your message.

### Example tweet:



**Tip:** Identify which representatives you want your message to reach on Twitter and be sure to follow their chief of staff, legislative assistant, and close network. You'll want to engage with their posts to ensure that when you share your messages, they'll show up in the right places to make an impact.

### Social Media Accounts Related to NBS:

You can amplify your message and those of others around NBS by following and engaging with accounts that are already raising awareness for the cause. Consider following **@EveryLifeOrg**, **@BabysFirstTest**, **@GlobalGenes**, **@RareDiseases**, or **@Eurordis**.



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