



## Turning Awareness Into Action: Tips for Advocating

This Dravet Syndrome Awareness Month, the theme is "Turning Awareness into Action." The focus is on how our community can come together to advocate for a better future and create actionable change for those impacted by a rare disease.

Recent federal funding cuts and staffing reductions at critical agencies like the NIH, FDA, and CDC threaten progress in rare disease research and patient care. The budget reconciliation bill passed by the House this month includes significant cuts to Medicaid which could impact our community. Now, more than ever, your voice can make a difference. Below are tips to help you turn your awareness into powerful advocacy:

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### 1. Speak from the Heart

Your personal story is your superpower. Whether you're a patient, caregiver, loved one, or an ally, sharing your experience helps lawmakers and the public understand why continued investment in rare disease research matters.

- Keep it short, honest, and focused
- Emphasize how research and access to care have impacted your life

### 2. Contact Your Elected Officials

Don't underestimate the power of a simple email, call, or social media post. Ask them to protect and prioritize Medicaid as well funding for rare disease research through the NIH, FDA, and CDC.

- Use our **pre-written email templates**, visit [advocatefordravet.org](https://advocatefordravet.org) to use our action alerts, or call their offices
- Be respectful and clear: "As your constituent, I urge you to support rare disease research funding and protect Medicaid."

### 3. Use Your Platform

Every post, tweet, or story adds to the movement. Use your voice on social media to raise awareness and call others to action.

- Tag your elected officials
- Use hashtags like **#AdvocateforDravet** and **#CureDravet**
- Share graphics and key facts from our toolkit
- Customize and use this [Canva Template](#) on social media

#### 4. Mobilize Your Circle

Encourage friends, family, and coworkers to join you in advocating. Many people want to help—they just need a nudge and the tools to do it.

- Host a letter-writing event or share our toolkit with your networks.
- Ask at least three people to contact their legislators as well.

#### 5. Take Daily Actions

Advocacy isn't just one big moment—it's a series of small, meaningful actions that add up.

- Download our **30 Days of Action Calendar** for small and big impact actions you can take each day this month. Reminder, advocacy is a marathon, not a sprint.
- Persistence is key to getting people to listen

#### 6. Remember: Every Voice Matters

You don't need to be a policy expert or have a huge following to make an impact. Lawmakers care about what *real people* in their communities think, especially when they speak from the heart.

- Whether you're making a call, sending an email, or sharing a post, **your voice adds to the chorus for change**
- When more of us speak up, it becomes impossible to ignore