



ANGELMAN SYNDROME ADVOCACY TOOLKIT

Introduction

The **Angelman Syndrome Advocacy Toolkit**, developed collaboratively by the **Angelman Syndrome Foundation (ASF)** and the **Foundation for Angelman Syndrome Therapeutics (FAST)**, equips advocates with the tools, knowledge, and confidence to raise awareness, influence policy, and drive meaningful change.

Our shared mission is to empower advocates to improve the quality of life for individuals living with Angelman syndrome (AS) and their families. Whether you're meeting with legislators, organizing community events, or raising awareness online, this toolkit is your comprehensive guide to making an impact.

1. Advocacy Basics

What is Advocacy?

Advocacy is the act of using your voice and actions to create change. For the Angelman syndrome community, advocacy encompasses:

- Raising awareness about Angelman syndrome and its impact on families.
- Supporting policies that improve access to care, therapies, and resources.
- Amplifying the needs and experiences of individuals and families living with Angelman syndrome.

Who can be an Advocate?

- **Parents and Family Members:** Share your lived experiences to help policymakers understand the challenges and needs of those with Angelman syndrome.
- **Siblings:** Brothers and sisters can provide a unique and powerful perspective, sharing how Angelman syndrome impacts the entire family.
- **Friends and Community Members:** Anyone passionate about making a difference can lend their voice to advocate for better policies and support.
- **Healthcare Providers:** Clinicians and therapists can highlight the medical and therapeutic needs of the Angelman community.
- **Educators:** Teachers and school staff can advocate for inclusive education and resources for children with Angelman syndrome.
- **AS Supporters:** Anyone connected to the mission of ASF or FAST can participate to amplify the message and drive meaningful change.

Advocacy is for everyone who wants to make a positive impact!

Why Your Voice Matters

Your personal story is powerful. Decision-makers are moved by real-life experiences and the passion of advocates who share them. By sharing your connection to Angelman syndrome, you can:

- Build awareness about the challenges and successes of the AS community.
- Highlight critical gaps in healthcare, research, and support systems.
- Influence policies and funding decisions to drive meaningful change.

2. Key Messages

The following information is to help ensure consistency and continuity in our messaging as we advocate for the Angelman syndrome community.

These key messages are designed to align our collective voice and strengthen the impact of our outreach efforts. By sharing the same core points, we can present a united front that amplifies awareness, drives meaningful change, and ensures that all audiences clearly understand our community's needs.

About Angelman Syndrome

- Angelman syndrome (AS) is a rare neurogenetic disorder that affects approximately **1 in 15,000 live births**.
- It primarily impacts the nervous system, causing developmental delays, lack of speech, seizures, and a distinctive happy demeanor.
- Currently, there are **no FDA-approved treatments** for AS, making research and advocacy vital.

Advocacy Focus Areas

- 1. Healthcare Access:**
 - Advocate for comprehensive medical care, including multidisciplinary AS clinics and therapies such as physical, occupational, and speech therapy.
- 2. Research Funding:**
 - Push for increased funding for Angelman syndrome research, including basic and translational research and clinical trials for emerging treatments.
- 3. Support for Families:**
 - Support policies that offer respite care, mental health resources, and financial assistance for caregivers.
- 4. Adult Care:**
 - Advocate for effective transition programs from pediatric to adult care, with a focus on long-term support and services for adults living with Angelman syndrome.

3. How to Advocate

A. Meet with Legislators

1. Prepare Your Story:

- Share a concise, emotional, and impactful narrative about how Angelman syndrome has affected your life or community.

2. Know Your Ask:

- Be specific about what you're requesting, such as increased research funding, support for a specific bill, or improved healthcare policies.

3. Follow Up:

- Send a thank-you note summarizing your key points and providing additional resources, like policy briefs or fact sheets.

B. Host Local Events

- Organize awareness walks, community fundraisers, or informational sessions to engage your local network.
- Use these events to educate attendees, recruit supporters, and build momentum for Angelman syndrome initiatives.

C. Leverage Social Media

- Share personal stories, advocacy opportunities, and educational content on platforms like Facebook, Instagram, and X (formerly Twitter).
- Use hashtags like **#AngelmanSyndrome**, **#AngelmanAdvocates**, **#AdvocateForAS**, and **#AngelmanStrong** and **#CureAngelman** to amplify your reach.

D. Write Letters or Emails

- Address letters to legislators, local leaders, or other stakeholders to request support for Angelman syndrome policies and initiatives.
- Include personal stories, compelling statistics, and clear requests for action.

Tips for Securing a Proclamation in Your State

Getting a proclamation issued by your state or local government can be a powerful way to raise awareness about Angelman syndrome and demonstrate community support. Here’s a step-by-step guide to help you through the process:

Step 1: Understand What a Proclamation Is

A proclamation is an official declaration issued by a government official, such as a governor, mayor, or county executive, to recognize a specific day, week, or month for awareness or celebration. For Angelman syndrome, this could be a proclamation for **Angelman Syndrome Awareness Day on February 15th**.

Step 2: Research Your Local Process (add link to the resource we currently have with links to each state)

Each state or locality may have a different process for requesting a proclamation. To get started:

- Visit your governor’s or mayor’s website to find information on proclamation requests.
- Look for a “**Proclamation Request**” section or similar instructions.
- Identify the submission guidelines, such as deadlines, required forms, or formats.

Step 3: Prepare Your Request

Your request should include:

1. A Draft Proclamation:
 - Keep it concise and focused on Angelman syndrome awareness.
 - Highlight key facts, such as the prevalence, impact on families, and need for awareness.
 - Example text:
 “WHEREAS, Angelman syndrome is a rare neurogenetic disorder affecting approximately 1 in 15,000 live births, characterized by developmental delays, seizures, and lack of speech; and
 WHEREAS, increased awareness can lead to earlier diagnosis, better care, and improved support for families;
 NOW, THEREFORE, I [Governor/Mayor’s Name], proclaim February 15th as Angelman Syndrome Awareness Day in [State/City].”
2. A Cover Letter or Email:
 - Introduce yourself and your connection to Angelman syndrome.
 - Explain why raising awareness is important and how the proclamation can help.
 - Thank the official for their time and consideration.
3. Supporting Documents:
 - Include fact sheets, personal stories, or statistics about Angelman syndrome to emphasize the importance of the proclamation.

Step 4: Submit Your Request

- Follow the submission instructions provided by the governor’s or mayor’s office.
- If no specific process is outlined, contact their office by phone or email to inquire about how to submit your request.

Step 5: Follow Up

- If you don’t hear back within a couple of weeks, follow up politely to check on the status of your request.
- Be prepared to answer any questions or provide additional information.

Step 6: Celebrate and Share

Once your proclamation is approved:

- Request a copy or an official ceremony where the proclamation is read or presented.
- Share the proclamation on social media, using hashtags like **#AngelmanSyndrome**, **#AngelmanAwareness**, **#AngelmanAdvocates** and **#ProclamationForAS**.

- Inform local media to generate additional awareness.
- Organize a small community event to commemorate the proclamation.
- Make sure you go to **AngelmanAdvocates.org** and let us know that you have received it and details.

Helpful Tips for Success

- **Start Early:** Many offices require proclamation requests to be submitted weeks or months in advance.
- **Be Persistent but Polite:** Advocacy often requires follow-ups, so don't hesitate to reach out again if needed.
- **Get Local Support:** Partner with other Angelman syndrome families or local organizations to demonstrate broader community interest.
- **Leverage Relationships:** If you know someone in government or have connections to local officials, ask them to support your request.

Resources for Getting Started

- **Sample Proclamation Templates:** Pre-written text you can customize for your state or city.
- **State Contact List:** Links to governor's offices and mayoral websites.
- **Advocacy Support:** Reach out to the Angelman Syndrome Foundation or FAST for guidance or assistance.

4. Resources

Sample Advocacy Scripts

1. Phone Call to Legislator:

"Hi, my name is [Your Name], and I'm a constituent from [Your City]. I'm calling to ask for your support in funding research and care for Angelman syndrome, a rare neurogenetic disorder. Families like mine urgently need better resources and treatments. Your support can make a difference. Thank you for your time."

2. Email Template:

"Dear [Legislator's Name],
My name is [Your Name], and I am a parent/caregiver/advocate for individuals living with Angelman syndrome. This rare disorder profoundly impacts families like mine. I'm asking for your support on [specific issue]. Together, we can improve access to care, advance research, and provide essential resources for the Angelman syndrome community. Thank you for considering this important cause.
Sincerely, [Your Name]"

Advocacy Tools (still in the works)

- **Angelman Fact Sheet:** A one-page overview of Angelman syndrome and key statistics.
- **Policy Briefs:** Summaries of key legislative issues affecting the Angelman syndrome community.
- **Social Media Toolkit:** Prewritten posts, graphics, and hashtags for sharing.
- **Letter Templates:** Ready-to-use templates for outreach to legislators or local leaders.
- **Event Planning Guide:** Step-by-step instructions for organizing awareness or fundraising events.

6. Current Advocacy Priorities

We understand that every family, community, and state faces unique circumstances and priorities. Whether it's accessing resources, advocating for policies, or supporting research efforts, each situation is personal and important.

The priorities and focus areas outlined in the attached document have been carefully developed through collaboration between the leadership teams at FAST and ASF. These priorities reflect a shared vision for progress, informed by deep engagement with the Angelman syndrome community and a commitment to addressing the diverse needs of families.

While individual needs may vary, these focus areas provide a unified foundation for advocacy and action. By working together and aligning our efforts, we can maximize the impact of our collective voice and bring meaningful change for individuals and families living with Angelman syndrome.

1. Increase funding for rare disease research through the **NIH and FDA**.
2. Advocate for caregiver support policies, such as paid family leave and financial aid for caregivers.
3. Expand Medicaid waivers to improve access to services for adults with developmental disabilities.

7. Contact Us

For more information, support, or assistance with advocacy efforts, reach out to:

AngelmanAdvocates.org

Together, we can create meaningful change for the Angelman syndrome community. Thank you for being a voice for advocacy.

For more resources please go to <https://thearc.org/advocacytoolkit>