

Infantile Spasms **Awareness Week** Partner Toolkit

#ISAW2016

December **1 - 7, 2016**



Infantile Spasms
AWARENESS
Little Seizures: BIG Consequences

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The Infantile Spasms Awareness Week partner toolkit is designed to support all partner and stakeholder outreach efforts around ISAW2016. The tools are customizable and uniformly branded to provide common messaging for the campaign.

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KEY MESSAGES

The following key messages should provide the foundation from which to draft any additional ISAW materials and offer guidance on how to communicate about the awareness week.

Infantile Spasms are serious.

Infantile spasms, or seizures, are rare, but serious.

Infantile spasms (IS) are subtle seizures occurring in children under age one. While rare, they can cause long-term damage to a child's developing brain.

- Infantile spasms are the result of a neurological condition and are characterized by repetitive, but often subtle movements—such as a jerking of the mid-section, raising of the arms or wide-eyed blinks.
- Infantile spasms occur in an estimated 30 percent of children with tuberous sclerosis complex (TSC).
- Often, infantile spasms occur in quick succession—in clusters of sometimes dozens at a time.
- About 2,500 children in the U.S. are diagnosed with infantile spasms each year.
 - They often start when a child is just a few months old and are slightly more common in boys.

Know the signs.

Identifying spasms is critical for parents, caregivers and providers.

Because infantile spasms can be mistaken for other conditions or seen as not harmful, prompt diagnosis and appropriate treatment are critical for the child's best developmental outcome.

- Most pediatricians will only see one or two IS cases throughout their entire career.
 - A qualified child neurologist can help confirm a diagnosis.
- If a parent or caregiver is concerned that infantile spasms has been overlooked, they need to broach the subject directly with their health care provider.
- The earlier a child is diagnosed, the greater the chances that the spasms can be treated.
 - Once the spasms are treated, a child's brain has more time to recover and gain developmental ground that may have been lost while the spasms occurred.
 - Many children respond well to treatment and go on to develop normally for their age.

Awareness leads to opportunity.

We're raising awareness in hopes of a brighter future.

Each year, Infantile Spasms Awareness Week (ISAW) provides a unique opportunity to discuss disease awareness and opportunity within the child neurology field.

- Held December 1-7, **Infantile Spasms Awareness Week** helps parents, as well as physicians and other health care providers, know about this disease and treatments.
 - ISAW provides a forum for distributing new research and recognizing exemplary contributions to the treatment of infantile spasms.
- The IS Hope Award honors a family that demonstrates courage in the face of their child's diagnosis, while using their experience to help generate awareness of IS and educate other parents facing this devastating form of seizures.
- To join the conversation on Twitter, use the hashtag [#ISAW2016](#) or visit [isweek.org](#). There is help! There is hope!

Research is critical.

We need more research about infantile spasms.

The first-ever preventive epilepsy trial in the United States specific to infantile spasms in tuberous sclerosis complex is beginning.

- About 80 percent of children with TSC develop epilepsy within the first three years of life, and infantile spasms occur in an estimated 30 percent of children with TSC.
- Some researchers believe that by identifying abnormal brain activity prior to the onset of seizures, we'll be able to intervene earlier and prevent infantile spasms or other types of seizures.
- The study will recruit 80 infants with TSC at seven sites across the country. Half will be treated with the drug Vigabatrin and the other half placebo—the standard of care right now. They will be assessed at 24 and 36 months of age for any developmental delays and signs of improvement.
- We welcome those interested to contact the Tuberous Sclerosis Alliance at 301.562.9890.

HTML STAKEHOLDER EMAIL

The HTML stakeholder email provided below can be sent to your constituents/members to encourage them to help promote ISAW. It contains a header/footer to embed in any email client for additional branding of ISAW. Upload the images to your email client (i.e. Constant Contact, Mail Chimp, Blue State Digital, etc.) and click “insert image” for the appropriate header/footer section and paste the text.

SUBJECT: Infantile Spasms: Raising Awareness in Hopes of a Brighter Future.

As part of our continued dedication to raising awareness of infantile spasms, we are participating in **Infantile Spasms Awareness Week (ISAW)**, and we hope you will join. Because infantile spasms can be mistaken for other conditions or appear subtly, prompt diagnosis and appropriate treatment are critical for a child’s best developmental outcome – and that’s why we’re dedicated to raising awareness of this disease.

But awareness is just the first step – we also need more research. The first ever preventive epilepsy trial in the United States specific to infantile spasms in tuberous sclerosis complex (TSC) is beginning! Some researchers believe that by identifying abnormal brain activity prior to the onset of seizures, earlier intervention could prevent infantile spasms or other types of seizures. The study will recruit 80 infants with TSC (infantile spasms occur in an estimated 30% of children with TSC) at seven sites across the country.

Efforts like ISAW bring together advocacy organizations, parent/caregivers, industry, and frontline providers to educate the public about infantile spasms. Held **December 1-7**, the goal is to increase awareness and understanding of infantile spasms through education, research, recognition of exemplary contributions to care and the declaration to patients and caregivers that **the future is bright**.

Please join us on social media using **#ISAW2016** and visit www.isweek.org.

HEADER



FOOTER



SAMPLE



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NEWSLETTER TEMPLATE

The newsletter sample provided below can be tailored with your organization's information and included in your newsletters and other communications materials.

Infantile Spasms Awareness Week Raising Awareness in Hopes of a Brighter Future.

Join **XXXX** in support of the annual **Infantile Spasms Awareness Week (ISAW)**. This week-long advocacy effort held **December 1-7** provides a unique opportunity to raise infantile spasms awareness within the child neurology community, learn about new advances in research and recognize exemplary contributions to the treatment of infantile spasms.

Parents/caregivers, physicians and advocacy organizations alike can join ISAW efforts by joining the conversation. Use the hashtag [#ISAW2016](#) and visit isweek.org.

SOCIAL MEDIA

The social media sample posts below can be customized for your organization. Generating a robust online dialogue around ISAW2016 is vital to spreading awareness about infantile spasms and engage with diverse communities who may not be aware of this devastating disease and the research, education and treatments available.

Tweets

- Infantile spasms is a rare, often misdiagnosed seizure disorder – Do you know the signs? #ISAW2016 isweek.org
- Join **@ORG HANDLE** to support children w/ infantile spasms Dec 1-7 #ISAW2016 isweek.org
- Infantile spasms: See the physical, know the neurological – Learn the signs of subtle seizures @ isweek.org #ISAW2016
- December 1 – Join #ISAW2016 Twitter chat to learn about infantile spasms & how to raise awareness
- On December 1 - Dr. Martina Bebin speaks w/ National/Local TV & Radio about IS & @UABSOM PREVeNT trial #ISAW2016
- Have you heard about infantile spasms? Learn the subtle signs of seizures @ isweek.org #ISAW2016
- Research is critical @UABSOM launches 1st preventive trial specific to TSC & IS – More info: isweek.org #ISAW2016

Facebook Posts

- Infantile spasms is the result of a neurological condition characterized by repetitive, but often subtle movements—such as a jerking of the mid-section, raising of the arms or wide-eyed blinks. About 2,500 children in the U.S. are diagnosed with infantile spasms each year. We're raising awareness in hopes of a brighter future. **Infantile Spasms Awareness Week** (December 1-7) helps parents, as well as health care providers, learn about this disease, treatments, and research. Join the conversation on Twitter at #ISAW2016 and visit isweek.org.
- Families impacted by infantile spasms (IS) understand the urgency of credible, fact-based education surrounding the disease. Knowing the right diagnosis can lead to the best care. **Infantile Spasms Awareness Week** (December 1-7) is an opportunity for parents, caregivers and providers to share IS information and research. Join the conversation on Twitter at #ISAW2016 and visit isweek.org.

Facebook Cover Photo

Show your support of ISAW by uploading the below ISAW2016 Facebook cover photo to your profile.

1. Save the cover photo:
 - a. Right click on the below image
 - b. Click "Save as picture"
 - c. Save to a folder or your desktop
2. Login to Facebook and go to your personal Facebook profile
3. Click the camera icon on your current cover photo that says "Change Cover"
4. Click Upload Photo from the dropdown
5. Upload the ISAW2016 cover photo from your designated folder/desktop
6. *Raise awareness!*

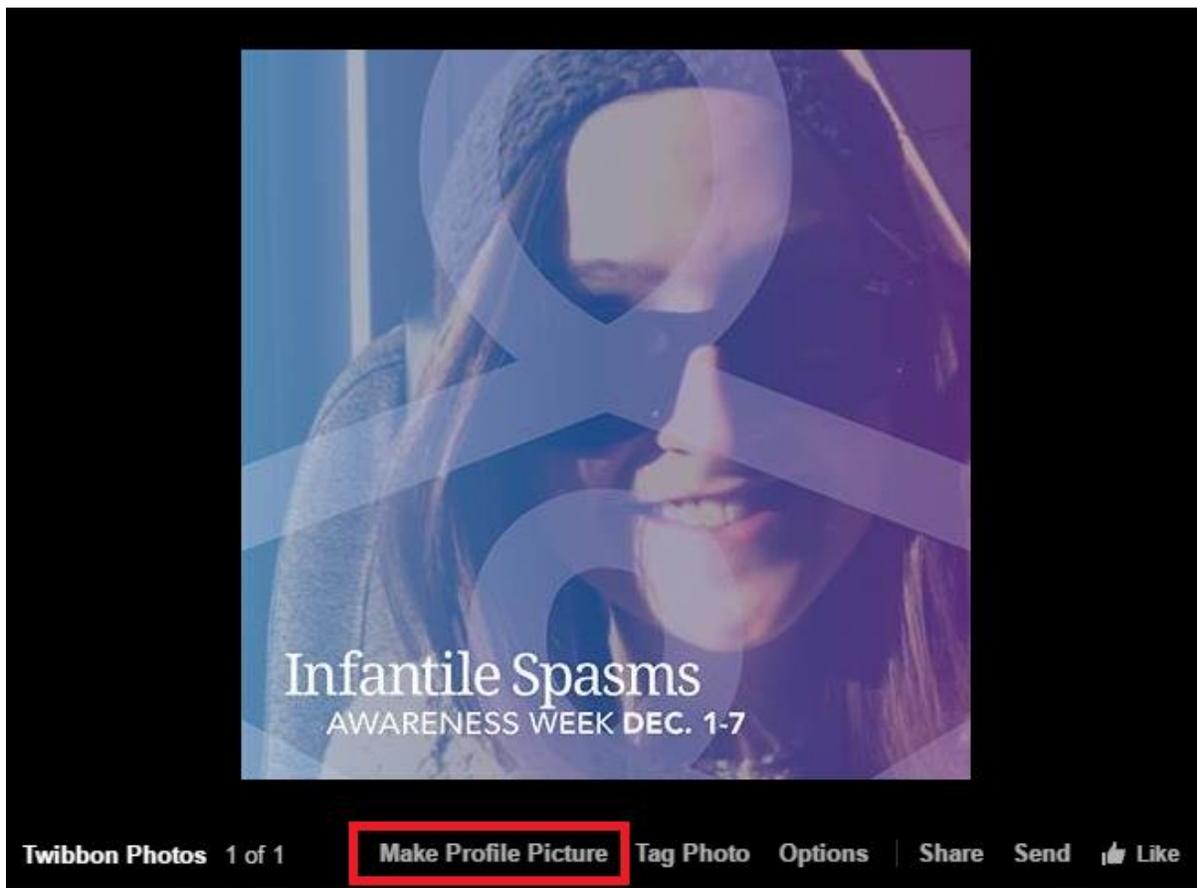


Facebook Profile Frame

Using our customized #ISAW2016 profile picture overlay, spark conversation and let your followers know that you support IS treatment, research and education.

Using Twibbon, you can easily apply an overlay to your current profile picture, following the instructions below:

1. Visit <http://twibbon.com/Support/isaw-2016> and click on the green “Add to Facebook” button.
2. Click on the green “Add the Twibbon to Facebook” button. At this time, you can opt to include a message of support that will post to your timeline when your overlay is uploaded.
3. Log-in through Facebook.
4. Confirm that you would like to “Set as your Facebook profile picture.”
5. Once on Facebook, click the “Make Profile Picture” button.
6. *Raise awareness!*



SOCIAL SHARES

Share these ISAW graphics on Twitter, Facebook, or even in your newsletters and on your organizations' websites.

1. Right click on the social share
2. Click "Save as picture"
3. Save to a folder or your desktop
4. Upload the file to your platform of choice –Facebook or Twitter— and share!



- Jerking at the tummy
- Arm raising
- Wide-eyed blinks

Know the signs of subtle seizures;
know the signs of infantile spasms.



PARTNERS IN AWARENESS

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

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Emergency Physicians®

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Tuberous Sclerosis Alliance

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EPILEPSY

 **ACNN**
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NEUROLOGY NURSES