



Infantile Spasms

Infantile Spasms Awareness Week

Partner Toolkit



Infantile Spasms
AWARENESS
Little Seizures: BIG Consequences

#ISAW2019
December 1-7, 2019

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This Infantile Spasms Awareness Week partner toolkit is designed to support all partners and stakeholder outreach efforts around ISAW2019. 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 (IS) are a medical emergency.

Infantile spasms are a rare, but very serious type of seizure.

Infantile spasms (IS) are seizures, usually occurring in children under age one, which are often overlooked. IS can cause catastrophic, permanent damage to a child's developing brain.

- ◆ Infantile spasms are caused by a condition in a baby's brain and include repetitive, but often subtle movements—such as jerking of the mid-section, dropping of the head, raising of the arms or wide-eyed blinks. IS can be misdiagnosed as colic, reflux, or a startle reflex.
- ◆ While infantile spasms appear as subtle movements – not as outwardly visible as grand mal or “convulsion” seizures – they are still a dangerous form of epilepsy.
- ◆ Often, infantile spasms occur in quick succession—sometimes dozens at a time. A baby can have more than 100 seizures in one day!
- ◆ Worldwide, it is estimated that a baby is diagnosed with infantile spasms every 12 minutes.
- ◆ Infantile spasms occur in up to 35 percent of children with tuberous sclerosis complex (TSC), a genetic disorder that causes tumors to form in various organs and the leading genetic cause of both epilepsy and autism.

Know the signs to 'STOP' Infantile Spasms.

Urgent identification is critical for parents, caregivers and providers.

Prompt diagnosis and treatment are critical, but this is challenging because infantile spasms can be mistaken for normal baby movements or other disorders that don't demand urgency.

- ◆ Pediatricians, emergency care physicians, and family practitioners are often the first to see a baby with infantile spasms (IS). Awareness of IS symptoms and prompt action are critical.
- ◆ Parents and caregivers often report that their concerns are not heard by their providers and infantile spasms are overlooked, but they should feel empowered to pursue more investigation.
- ◆ The earlier a child is diagnosed, the greater the chances that the spasms can be effectively treated.



- ◆ A helpful mnemonic tool – an easily remembered acronym—is ‘STOP’ Infantile Spasms:
 - ◆ **See the signs:** *Clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching.*
 - ◆ **Take a video:** *Record the symptoms and talk to your doctor immediately.*
 - ◆ **Obtain diagnosis:** *Confirm an irregular brain wave pattern with an EEG test.*
 - ◆ **Prioritize treatment:** *End spasms to minimize developmental delays*
- ◆ To download the **STOP IS graphic elements**, including the logo and animated video, [click here](#).
 - ◆ Select the file you’d like to access and click on the “Download” button in the top right corner.
- ◆ For assistance downloading the materials, please contact Altaira Northe at anorthe@childneurologyfoundation.org .
- ◆ The animated video can also be shared via YouTube: <https://youtu.be/rCC92Q52hdk>.

We’re raising awareness about Infantile Spasms in hopes of a brighter future.
Awareness leads to opportunity!

Each year, Infantile Spasms Awareness Week (ISAW) provides a unique opportunity to discuss disease awareness 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.
- ◆ To join the conversation on Twitter, use the hashtag [#ISAW2019](#) or visit isweek.org. Together we can STOP IS!

Research is critical.
Research about infantile spasms is gaining momentum.

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

- ◆ About 80 percent of children with TSC develop epilepsy within the first three years of life, and infantile spasms occur in up to 35 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 15 sites across the country and aims to determine the impact of preventive treatment with Vigabatrin on the developmental outcomes of children



at two years of age. We welcome those interested to contact the Tuberous Sclerosis Alliance at www.tsalliance.org or 800-225-6872.

- ◆ A clinical trial is recruiting newly diagnosed infants (aged 1-24 months) with infantile spasms to see if cannabidiol (CBD), used in combination with Vigabatrin for the treatment of IS, is better than Vigabatrin alone. To learn more, visit: www.childneurologyfoundation.org/providers-or-researchers/clinical-trials-directory



Social Media

The sample social media posts below are customizable for your organization. Generating a robust online dialogue around ISAW2019 is vital to spreading awareness about infantile spasms and engaging with diverse communities who may not be aware of this devastating disease and the research, education, and treatments available.

TWEETS

- ◆ Worldwide, a baby is diagnosed with infantile spasms every 12 minutes, but we can help. Awareness leads to opportunity! #ISAW2019 [attach photo of mnemonic]
- ◆ What are infantile spasms? They are a medical emergency. Check out these videos to know what to look for #ISAW2019 <http://www.childneurologyfoundation.org/disorders/infantile-spasms/>
- ◆ To help remember what's important, 'STOP': [S]ee the signs, [T]ake a video, [O]btain diagnosis, [P]rioritize treatment. #ISAW2019 [attach photo of mnemonic]
- ◆ Infantile spasms may not look like the typical "convulsion" seizure, but they're equally as dangerous. Learn more at www.isweek.org #ISAW2019
- ◆ Subtle jerking, arm-raising, wide-eyed blinks – know the signs to 'STOP' Infantile Spasms #ISAW2019 www.isweek.org [attach photo of mnemonic]
- ◆ Infantile spasms are often overlooked, which is why early diagnosis is crucial for treatment. START the conversations to 'STOP' IS #ISAW2019 www.isweek.org [attach photo of mnemonic]
- ◆ Research is critical and the momentum is gaining. Help @tsalliance recruit infants to study this rare disorder. For more info: www.isweek.org
- ◆ STOP: [S]ee the signs, [T]ake a video, [O]btain diagnosis, [P]rioritize treatment to diagnose Infantile Spasms #ISAW2019 [attach photo of mnemonic]
- ◆ STOP to [S]ee the signs. STOP to [T]ake a video. STOP to [O]btain a diagnosis. STOP to [P]rioritize treatment. #ISAW2019 [LINK to VIDEO]
- ◆ Infantile spasms cause catastrophic & permanent damage to a child's developing brain. Learn more about this RARE, but SERIOUS seizure condition at www.isweek.org #ISAW2019



FACEBOOK POSTS

- ◆ Infantile spasms (IS) are subtle, but serious, seizures that occur in infants as the result of a neurological condition. Worldwide, it's estimated that a baby is diagnosed with IS every 12 minutes. We're coming together for Infantile Spasms Awareness Week (Dec. 1-7) to raise awareness for this serious medical emergency. Together, with your help, we can more quickly diagnose Infantile Spasms. For more info visit www.isweek.org and join the conversation at #ISAW2019.
- ◆ Awareness leads to opportunity! Infantile Spasms Awareness Week 2019 is December 1-7. Join us as we raise awareness of the subtle signs; educate parents, providers, and caregivers on how to obtain diagnosis; and build momentum for critical IS research. Start the conversation to 'STOP' infantile spasms and improve the lives of thousands of children. Visit www.isweek.org to learn more and join the conversation on Twitter at #ISAW2019.
- ◆ December 1-7 is Infantile Spasms Awareness Week 2019. As parents, providers, caregivers, and concerned individuals, we can more quickly diagnose infantile spasms with the help of this easy-to-remember mnemonic tool: [S]ee the signs, [T]ake a video, [O]btain a diagnosis, and [P]rioritize treatment! Visit www.isweek.org for more information on this neurological condition and for tools to spread the word #ISAW2019.
- ◆ Spread the word to 'STOP' Infantile Spasms during Infantile Spasms Awareness Week 2019 (December 1-7). See the signs, Take a video, Obtain a diagnosis, and Prioritize Treatment to get babies with this serious condition the prompt diagnosis they need to live a healthier life. The earlier a child is diagnosed, the greater the chances that the spasms can be effectively treated. Check out www.isweek.org for more info and join the conversation on Twitter with #ISAW2019.
- ◆ Infantile spasms cause catastrophic & permanent damage to a child's developing brain. While IS may not look like the typical "convulsion" seizure, they're equally as dangerous. Learn more about this RARE, but SERIOUS seizure condition at www.isweek.org and join the conversation on Twitter with #ISAW2019



Facebook Cover Photo

Show your support of ISAW by uploading the below ISAW2019 Facebook cover photo to your profile.

EASY HOW-TO INSTRUCTIONS:

1. Save the cover photo:
 - ◆ Right-click on the below image
 - ◆ Click "Save as picture"
 - ◆ Save to a folder or your desktop
2. Log in 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 ISAW2019 cover photo from your designated folder/desktop
6. Raise awareness!



Facebook Profile Picture Overlay

Using our customized #ISAW2019 profile picture overlay, spark conversation and let your followers know that you support IS treatment, research and education.

EASY HOW-TO INSTRUCTIONS:

1. Log-in through Facebook.
2. Navigate to your profile page.
3. Hover your cursor over your profile picture, select "Update profile picture"
4. Select "Add Frame"
5. Search for "Child Neurology Foundation"
6. Select the "ISAW2019" frame and click "Use as Profile Picture"
7. Raise awareness!



Social Share Graphics

Share these ISAW2019 graphics on Twitter, Facebook, or even in your newsletters and on your organizations' websites.

EASY HOW-TO INSTRUCTIONS:

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!



Stakeholder Email



Send the HTML stakeholder email provided below to your constituents/members to encourage them to help promote ISAW2019. It contains a header/footer to embed in any email client for additional branding of ISAW2019. Upload the images to your email client (e.g. Constant Contact, Mail Chimp, Blue State Digital, etc.) and click “insert image” for the appropriate header/footer section and paste the text.

Subject Line: START the Conversation. STOP Infantile Spasms.

Infantile spasms (IS) are a medical emergency and are a rare, but very serious type of seizure. Infantile spasms usually occur in children under age one, are often overlooked, and can cause catastrophic, permanent damage to a child’s developing brain. Prompt diagnosis and treatment are critical, but this is challenging because Infantile Spasms can be mistaken for normal baby movements or other disorders that don’t demand urgency. Because they are more subtle than a typical grand mal or “convulsion” seizure, members of the [Infantile Spasms Action Network](#) have established ‘STOP’ Infantile Spasms to help people remember what’s most important when recognizing the disease’s subtle symptoms:

- ◆ **See the signs:** clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching
- ◆ **Take a video:** record the symptoms and talk to your doctor immediately
- ◆ **Obtain diagnosis:** confirm an irregular brain wave pattern with an EEG test
- ◆ **Prioritize treatment:** end spasms to minimize developmental delays

We ask you to join us in spreading this important message. Parents and caregivers often report that their concerns are not heard by their providers and Infantile Spasms are overlooked, they should feel empowered to pursue more investigation. As we approach Infantile Spasms Awareness Week (ISAW) 2019, your contribution to this conversation means so much. Take part December 1-7 at #ISAW2019 to learn more about the progress being made in Infantile Spasms.

To download the **STOP IS graphic elements**, including the logo and animated video, [click here](#). For assistance downloading the materials, please contact Altaira Northe at anorthe@childneurologyfoundation.org.





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ISWeek.org



Newsletter Template

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

Infantile Spasms Awareness Week, December 1-7

Know the signs to STOP Infantile Spasms.

Mark your calendars for the fourth annual Infantile Spasms Awareness Week (ISAW), December 1-7! Join **ORG NAME** as we continue the conversation around infantile spasms advocacy, research, and recognition for this medical emergency that too often goes overlooked. Together we can build awareness and more quickly diagnose infantile spasms to improve the future of thousands of children.

Advancing the conversation on infantile spasms begins with recognizing the symptoms. Use this mnemonic tool to '**STOP**' Infantile Spasms: **S**ee the signs, **T**ake a video, **O**btain diagnosis, **P**rioritize treatment.

Use the hashtag #ISAW2019 and check out www.isweek.org for more information.

To download the **STOP IS graphic elements**, including the logo and animated video, [click here](#). To receive a detailed copy of the logo usage guidelines, or for assistance downloading the materials, please contact Altaira Northe at anorthe@childneurologyfoundation.org.

You can share our animated video with your networks and internal organization on YouTube: <https://youtu.be/rCC92Q52hdk>.

You can also share the Brain Recovery Project's video that includes real life footage: <https://www.youtube.com/watch?v=KaZhg0NK5Dg&t=2s>



Mnemonic Logo Kit and Graphic Set

The intention of the 'STOP' Infantile Spasms mnemonic is to help start a conversation with the public and to act quickly when a child may be displaying symptoms recognized as Infantile Spasms.

	See the signs	Clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching
	Take a video	Record the symptoms and talk to your doctor immediately
	Obtain diagnosis	Confirm an irregular brain wave pattern with an EEG test
	Prioritize treatment	End spasms to minimize developmental delays

Infantile Spasms

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- ◆ The animated video can also be shared via YouTube: <https://youtu.be/rCC92Q52hdk>.
- ◆ The live video can be shared via YouTube: <https://www.youtube.com/watch?v=KaZhg0NK5Dg&t=2s>



Members of the Infantile Spasms Action Network include:

[American Academy of Neurology](#)

[American Academy of Pediatrics](#)

[American College of Emergency Physicians](#)

[American Epilepsy Society](#)

[Assertio](#)

[Association of Child Neurology Nurses](#)

[Bcureful](#)

[Belgium TSC](#)

[The Brain Recovery Project: Childhood Epilepsy](#)

[Surgery Foundation](#)

[Bridge the Gap - Syngap](#)

[Child Neurology Foundation](#)

[Child Neurology Society](#)

[CURE Epilepsy](#)

[Danny Did Foundation](#)

[Duke University Hospital](#)

[Dup15q Alliance](#)

[Epilepsy Foundation of America](#)

[FamilySCN2A Foundation](#)

[Global Genes](#)

[Greenwich Biosciences](#)

[Hope for HIE](#)

[LGS Foundation](#)

[Mallinckrodt Pharmaceuticals](#)

[Mickie's Miracles](#)

[National Organization for Rare Disorders
\(NORD\)](#)

[RARE Science](#)

[RING 14 International](#)

[Seizure Tracker](#)

[Tuberous Sclerosis Alliance](#)

[The UK Infantile Spasms Trust \(UKIST\)](#)

[Upsher-Smith Laboratories](#)

