

# STOP Infantile Spasms

Infantile Spasms Awareness Week  
**2020 PARTNER TOOLKIT**



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## Key Messages

The following key messages should provide the foundation for any ISAW outreach and offer guidance on how to communicate about the awareness week:

*Every day you delay increases your child's risk for brain damage.*

### ABOUT INFANTILE SPASMS

- Infantile spasms (IS) are a rare, but serious type of seizure, occurring in 1 in 2,000 children, which can cause catastrophic, permanent damage to a child's developing brain.
- The seizures include repetitive, but often subtle movements — including jerking of the mid-section, dropping of the head, raising of the arms or wide-eyed blinks.
- The onset of IS peaks between four and six months of age, although these seizures can begin anytime in the first two years.
- Infantile spasms are often overlooked or misdiagnosed for other conditions, including colic, reflux, or a startle reflex.
- Worldwide, it is estimated that a baby is diagnosed with IS every 12 minutes.

### FOR CAREGIVERS AND PARENTS

- As we navigate through the new reality of the COVID-19 pandemic, it's critical to remember that infantile spasms are a medical emergency that should never be taken lightly.
- Any delay in seeking emergency treatment can increase your child's risk for brain damage.
- Soon after the spasms begin, children may stop making developmental progress or even lose skills they had previously acquired, causing significant cognitive disabilities if left untreated.
- If caregivers believe their concerns are being overlooked, they should pursue a second opinion at a TSC clinic, a Comprehensive Pediatric Epilepsy Center, or from a neurologist with expertise in treating IS.
- Follow the mnemonic tool 'STOP':
  - **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.

## FOR HEALTHCARE PROVIDERS

- This Infantile Spasms Awareness Week (ISAW), healthcare providers — who are at the frontline of correct diagnosis and care — are reminded not to overlook the emergency of Infantile Spasms (IS) in the face of the COVID-19 pandemic. The earlier a child is diagnosed, the greater the chances that the spasms can be effectively treated.
- Because of COVID-19, the number of infantile spasms diagnosis in the U.S. has decreased in 2020 not because there are fewer cases but because families are fearful of going to hospitals during the pandemic.
- Research shows that by identifying abnormal brain activity prior to the onset of seizures, healthcare providers will be able to intervene earlier and prevent infantile spasms or other types of seizures.
- Clinicians should instruct parents to obtain and share video recordings of several consecutive typical events for review prior to the initial clinical encounter.
- Providers should help balance parents' concerns around contracting COVID-19 in a hospital setting with the emergency nature of infantile spasms. Clinicians should remind patients that anything that would have prompted them to bring their child to the emergency department in the past still warrants a visit now.

## Social Media Posts

The sample social media posts below are customizable for your organization. Generating a robust online dialogue around **#ISAW2020** 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

- 🛑 STOP:  
[S]ee the signs  
[T]ake a video  
[O]btain diagnosis,  
[P]rioritize treatment  
Every day you delay is a risk. #ISAW2020 [attach photo of mnemonic]
- RT to help raise awareness of infantile spasms and save a baby's life! ❤️ Learn more at [www.infantilespasms.org](http://www.infantilespasms.org) #ISAW2020
- 🛑 Infantile spasms are a medical emergency. Know the signs to look for and join the conversation with #ISAW2020 [link to video]
- Every day you delay recognizing the signs of IS and seeking help increases your child's risk of brain damage. Learn why infantile spasms are a medical emergency all new parents should know about at [www.infantilespasms.org](http://www.infantilespasms.org) #ISAW2020
- Raise your hand if you're a new parent 🙋🙋 We need your help to 'STOP' infantile spasms and improve the lives of thousands of children. #ISAW2020 [attach photo of mnemonic]
- Don't let COVID-19 stop you from seeking medical treatment for your child's infantile spasms. Follow #ISAW2020 to learn the signs and help spread awareness!
- Worldwide, a baby is diagnosed with infantile spasms every 12 minutes. 😲 Help spread awareness of this rare, but serious condition. Learn how you can help at [www.infantilespasms.org](http://www.infantilespasms.org) #ISAW2020
- Start the conversation to 'STOP' infantile spasms. 🟠 #ISAW2020 [attach photo of mnemonic]
- Infantile spasms can cause permanent damage to a child's developing brain. Early diagnosis is 🔑. Learn more here: [www.infantilespasms.org](http://www.infantilespasms.org) #ISAW2020
- Infantile spasms most often occur between 4 & 6 months of age but can begin anytime in the first 2 years. Know the signs to look for in your baby: [www.infantilespasms.org](http://www.infantilespasms.org) 📱 #ISAW2020

## FACEBOOK POSTS

- Did you know? Worldwide, it's estimated a baby is diagnosed with infantile spasms every 12 minutes. We're coming together for Infantile Spasms Awareness Week (Dec. 1–7) to raise awareness for this serious medical emergency. With your help, we can more quickly diagnose Infantile Spasms. Visit [www.infantilespasms.org](http://www.infantilespasms.org) for info and join the conversation with #ISAW2020.
- STOP. ●  
[S]ee the signs  
[T]ake a video  
[O]btain a diagnosis  
[P]rioritize treatment  
Every day you delay is a risk. Learn more about Infantile Spasms Awareness Week (Dec. 1–7) at [www.infantilespasms.org](http://www.infantilespasms.org) and join the conversation with #ISAW2020.
- Calendar alert 📅 Infantile Spasms Awareness Week 2020 is December 1–7. Join us as we educate parents, providers, and caregivers on how to recognize the subtle signs of IS and build momentum for critical research. Visit [www.infantilespasms.org](http://www.infantilespasms.org) to learn more and join the conversation with #ISAW2020.
- We need your help starting the conversation to 'STOP' infantile spasms and improve the lives of thousands of children. Infantile Spasms Awareness Week 2020 is coming up, December 1–7! Join the conversation with #ISAW2020 and visit [www.infantilespasms.org](http://www.infantilespasms.org) to learn more.
- We know COVID-19 has caused parents to worry, but time is of the essence when it comes to getting a diagnosis and treatment for infantile spasms. Join the conversation for Infantile Spasms Awareness Week (Dec. 1–7) with #ISAW2020 and learn why parents must prioritize the emergency of IS over COVID-19 fears at [www.infantilespasms.org](http://www.infantilespasms.org).

## Facebook Cover Photo

Show your support of ISAW by uploading the below ISAW2020 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 ISAW2020 cover photo from your designated folder/desktop
6. Raise awareness!



## Facebook Profile Picture Overlay

Spark conversation using our customized ISAW2020 profile picture overlay 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 “ISAW2020” frame and click “Use as Profile Picture”
7. Raise awareness!



## Social Share Graphics

Share these ISAW2020 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!



## 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.

To download the STOP IS graphic elements, including the logo and animated video, [click here](#).

- Select the file you'd like to access, select the three dots in the top right corner and click on the "Download" button.
- For assistance downloading the materials, please contact Mellissa Gallagher at [mellissa@gebencommunication.com](mailto:mellissa@gebencommunication.com).
- The animated video can also be shared via YouTube: <https://youtu.be/rCC92Q52hdk>.

**S** **T** **O** **P**  
Infantile Spasms

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

Infantile spasms are a rare, but serious type of seizures occurring in 1 in 2,000 children

Infantile spasms are often overlooked or misdiagnosed for other conditions, including colic, reflux, or a startle reflex

The onset of IS peaks between four and six months of age, although seizures can begin anytime in the first two years

Worldwide, it is estimated that a baby is diagnosed with IS every 12 minutes

*Every day you delay you increase your child's risk for brain damage.*

**S** **T** **O** **P**  
Infantile Spasms

*Every day you delay you increase your child's risk for brain damage.*

<p><b>SEE THE SIGNS</b> Clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching</p>	<p><b>TAKE A VIDEO</b> Record symptoms and talk to your doctor immediately</p>
<p><b>OBTAIN DIAGNOSIS</b> Confirm an irregular brain wave pattern with an EEG test</p>	<p><b>PRIORITIZE TREATMENT</b> End spasms to minimize developmental delays</p>

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Worldwide, it is estimated that a baby is diagnosed with IS every 12 minutes

## Spanish Social Share Graphic

A Spanish version of one of the social share graphics is also available to download.

### 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!



# Spanish Mnemonic Graphic Set

Spanish versions of the mnemonic graphic set are also available to download.

To download the Spanish STOP IS graphics, [click here](#).

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**S** **T** **O** **P**

## Síndrome de West

Señale los signos	Tome un video	Obtenga un diagnóstico	Priorice el tratamiento
Salvas repentinas, repetitivas de movimientos incontrolados como caída de cabeza o flexiones del cuerpo	Grabe los síntomas y hable con su médico inmediatamente	Confirme el trazado irregular cerebral con un EEG	Controle los espasmos para minimizar los retrasos del desarrollo



Síndrome de West es raro pero serio y ocurre en 1/2000



El síndrome de West muchas veces puede confundirse con otras condiciones como reflujo, cólicos o sobresaltos



Su aparición suele darse entre los 4 y los 6 meses de vida aunque las crisis pueden aparecer en cualquier momento antes de los dos años



Se estima que en el mundo se diagnostica a un niño con síndrome de West cada 12 minutos

*Cada día que pasa se incrementan los riesgos de daño cerebral en su hijo*

## STOP Síndrome de West

*Cada día que pasa se incrementan los riesgos de daño cerebral en su hijo*



### SEÑALE LOS SIGNOS

Salvas repentinas, repetitivas de movimientos incontrolados como caída de cabeza o flexiones del cuerpo



### TOME UN VIDEO

Grabe los síntomas y hable con su médico inmediatamente



### OBTenga UN DIAGNÓSTICO

Confirme el trazado irregular cerebral con un EEG



### Priorice EL TRATAMIENTO

Controle los espasmos para minimizar los retrasos del desarrollo



Síndrome de West es raro pero serio y ocurre en 1/2000



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