SPOT SMA

SYMPTOMS MILESTONES ACTION



Be a #SpotSMA Champion.
Use your voice.
Share your experience.
Help more people #SpotSMA.

Spinal Muscular Atrophy uk
SUPPORTING • INFORMING • ADVOCATING

Take #SpotSMA to your community. One conversation could help a family recognise the signs sooner.

If you have a connection to SMA and a platform or community you can reach, you can play an important part in helping more people recognise the signs of SMA.

As a **#SpotSMA Champion,** we're asking you to use your voice, your experience and your profile to help spread the campaign until we have newborn screening for SMA across the whole of the UK.

There isn't one right way to get involved. You might make a video, share your diagnosis story, take some #SpotSMA resources to your local GP surgery, your childs school or nursery or simply share campaign content with your followers.

Every action helps get information about SMA in front of more people.

SPOT SMA

Your #SpotSMA Challenge

Some ideas to help spread the campaign:

- □ Share your diagnosis story
- □ Make a #SpotSMA video
- □ Take resources to a GP surgery
- □ Share resources with a health visiting team
- □ Take resources to a nursery, children's centre or Family Hub
- □ Share #SpotSMA with a healthcare professional you know
- □ Share campaign content with your followers
- □ Ask another person with a platform to join the campaign
- □ Post a photo or video showing where you've taken #SpotSMA
- □ Come up with your own way to spread the word

1. Take #SpotSMA into your community

Help us get #SpotSMA resources into the places where babies and young children are seen.

You could take or send resources to:

- your local GP surgery
- health visiting teams
- children's centres and Family Hubs
- nurseries and other early-years settings
- maternity or midwifery services
- paediatric services
- other relevant local healthcare settings.



Turn it into content: Film a short clip of yourself taking the resources along.

It doesn't need to be polished. A simple video outside the building could say:

"I'm dropping off some #SpotSMA resources at my local GP surgery today. SMA is rare, so raising awareness of the signs really matters. This is one small thing we can all do to help spread the word until we have newborn screening across the UK."

“Taking #SpotSMA to my local GP surgery."

"These resources are heading to our local health visiting team."

"I've just dropped #SpotSMA resources at our local nursery."

"One more place where professionals can learn about the signs of SMA."

With permission, SMA UK may be able to share Champion activity to inspire others to take part.

Remember to ask permission before filming staff, patients or children.

Whenever you take action, we'd love you to tell us. Take a photo with the resources, make a quick video or post a Story and tag **SMA UK** and use **#SpotSMA.**

2. Share your diagnosis story



Personal stories can help people understand why recognising the signs of SMA matters.

If you're comfortable sharing your experience, make a short video or post about your own diagnosis, or your child's diagnosis.

You could talk about:
What were the first signs?
What did you or the people around you notice?

What happened next?
Who did you speak to and what was your route to diagnosis?

What do you wish people had known?
Was there something you now recognise as a possible sign of SMA?

Why are you supporting #SpotSMA?
What would you like healthcare professionals, early-years professionals or other families to know?

Your story doesn't need to represent everyone's experience of SMA. It's simply your experience, in your own words.

3. Make a quick #SpotSMA video



Short videos can be one of the easiest ways to reach people.

Try starting with:
"Before my diagnosis, we didn't know..."

"One of the first signs of SMA for us was..."

"I want more health professionals to know..."

"Here's why I'm supporting #SpotSMA..."

"Today I'm taking #SpotSMA to becasue..."

Keep it natural.
A 20–60 second portrait video filmed on your phone is absolutely fine.

4. Make it personal to your audience



Think about why the people who follow you might care.

If you're a parent, talk about your experience of noticing early signs.

If you're an adult living with SMA, share what you wish professionals or families had known about SMA.

If you're a healthcare professional, talk about why awareness of rare conditions matters.

If you're a content creator or influencer, use your platform to introduce #SpotSMA to an audience that might otherwise never encounter it.

If you're connected with a local community, challenge people to get #SpotSMA resources into services across your town or area.

5. Tag a friend & keep #SpotSMA moving



One person sharing #SpotSMA can lead to another person getting involved, and another.

Once you've taken your #SpotSMA action, tag or nominate someone else to do the same.

It could be a friend, another SMA family, someone in your community, a healthcare professional, or another influencer or content creator.

Try ending your post or video with:
"I've done my bit to help #SpotSMA, now I'm tagging @_____ to take #SpotSMA into their community. Where will you take it?"

Or keep it really simple:
"I'm tagging @_____ to help me spread the word. Who will you tag next? #SpotSMA"

Start a #SpotSMA chain
Take it. Share it. Tag someone. Keep #SpotSMA moving.

However you choose to support our SpotSMA Campaign, Thank you.

Every action helps get information about SMA in front of more people.

READ MORE



This campaign is funded by Novartis, Biogen and Roche they had no involvement or influence over the content and development of the campaign or materials.

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