



SPOT
SMA

**SYMPTOMS
MILESTONES
ACTION**



STARTING IN A FEW MINUTES AT 15:00

**Spot the Signs. Change a Life: The important role
of health visiting in early identification of SMA**

18 June 2026

#iHVInsights

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SMA **SYMPTOMS**
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Spot the Signs. Change a Life: The important role of health visiting in early identification of SMA

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Welcome



Make the most of the opportunity



Enjoy the whole hour



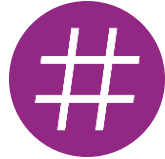
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- **Name of presenter** you would like to answer your question
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Feedback

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Continue your CPD:

- Access recording of live session after the event on our website (no recording on other devices is allowed)
- Attendance at this event and engagement with the iHV reflection template will support you with demonstrating CPD activities that align to the 2022 NMC Standards of Proficiency for SCPHN Health Visiting.

The Institute of Health Visiting is a charity and centre of excellence for health visiting. Its core purpose is:
To improve outcomes for children and families and reduce health inequalities through strengthened health visiting services

#iHVInsights

Spot the Signs. Change a Life: The important role of health visiting in early identification of SMA

Agenda



Welcome: Vicky Gilroy – Director of Innovation and Research, iHV

Guest Speakers

- Dr Mariacristina Scoto – Consultant Paediatric Neurologist, Great Ormond Street Hospital for Children
- Portia Thorman – Head of Advocacy and Community, SMA UK
- Kathryn Danagher – Health Visitor, North Tyneside Council
- Victoria Jackson - Health Visiting Lead - Professional Services, iHV

Q&A with Speakers

Close and Evaluation

Next speaker



Dr Mariacristina Scoto

Consultant Paediatric Neurologist,
Great Ormond Street Hospital for
Children



Type your questions as you
think of them during the
presentations

Use the Zoom Q&A function

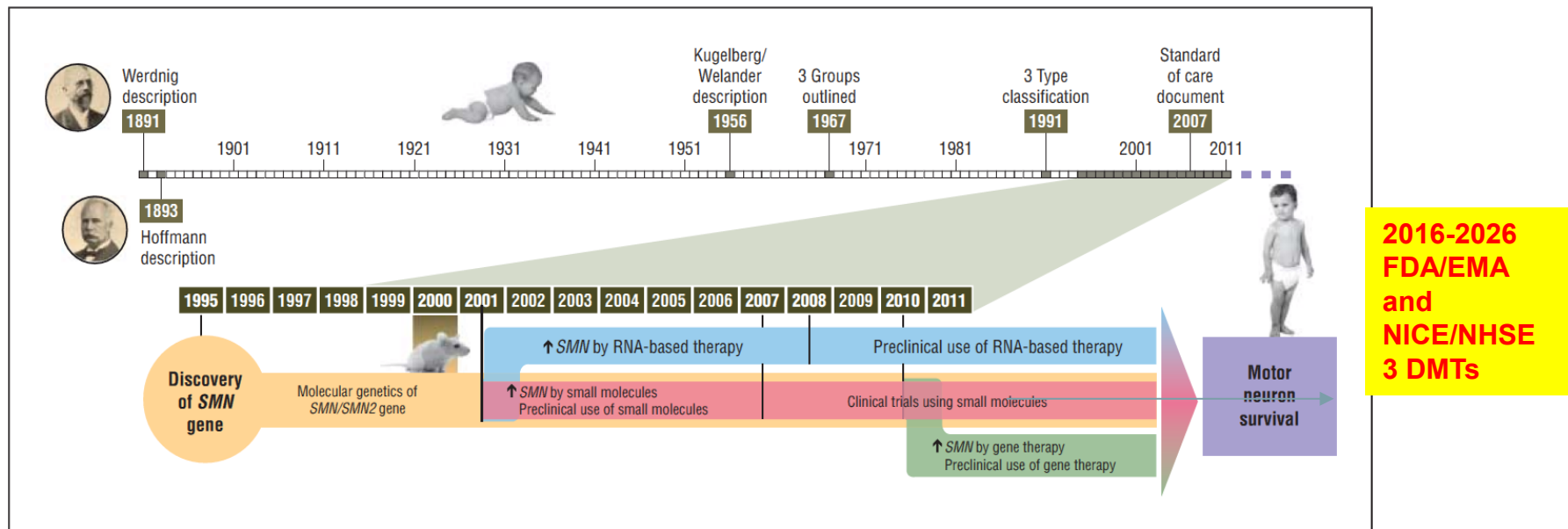
- **Name of presenter** you would like to answer your question
- Brief **question**
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Spinal Muscular Atrophy: disease overview and spot the sign

Dr Mariacristina Scoto MD, PhD

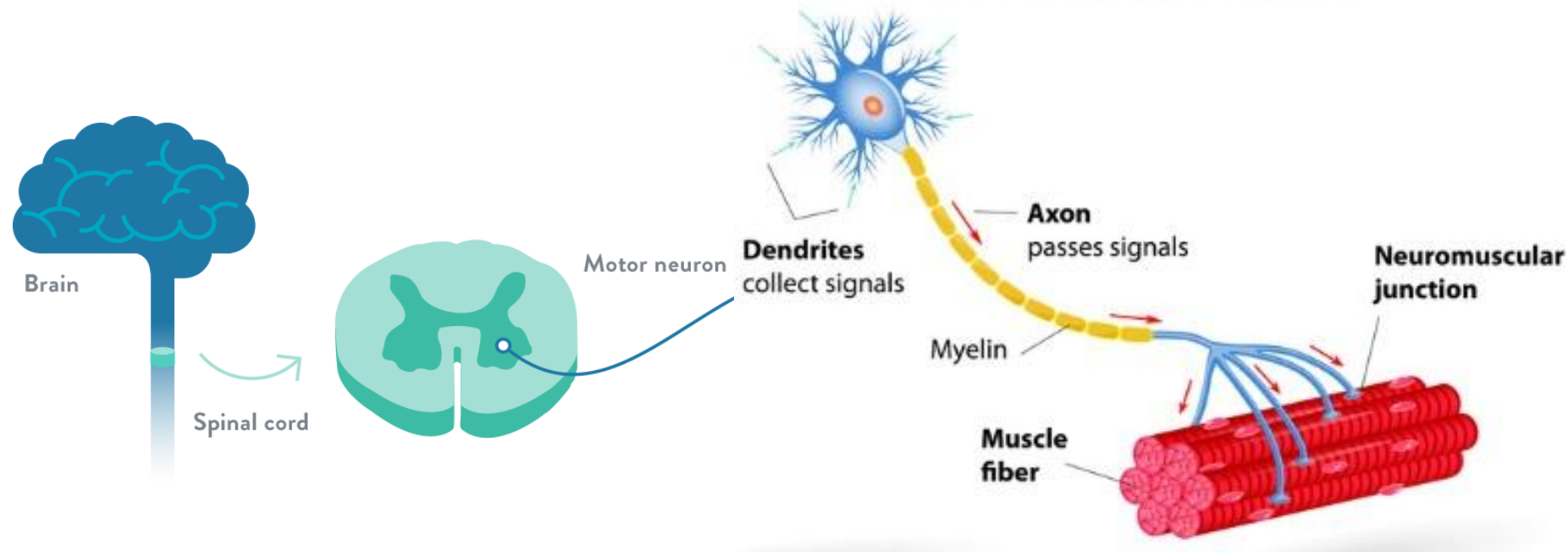
Consultant in Neuromuscular Translational Research
Great Ormond Street Hospital for Children &
UCL, Great Ormond Street Institute of Child Health/London, UK

Spinal Muscular Atrophy: Timeline



Spinal Muscular Atrophy: A Timely Review. Stephen J. Kolb, MD, PhD; John T. Kissel, MD; Arch Neurol. 2011;68(8):979-984

MOTOR NEURON



- Pan-ethnic incidence of approximately 1 in 11,000 live births (60% born with most severe form)
- Carrier frequency of 1 in 40 to 67

V. Dubowitz/Neuromuscular Disorders 19 (2009) 69–73

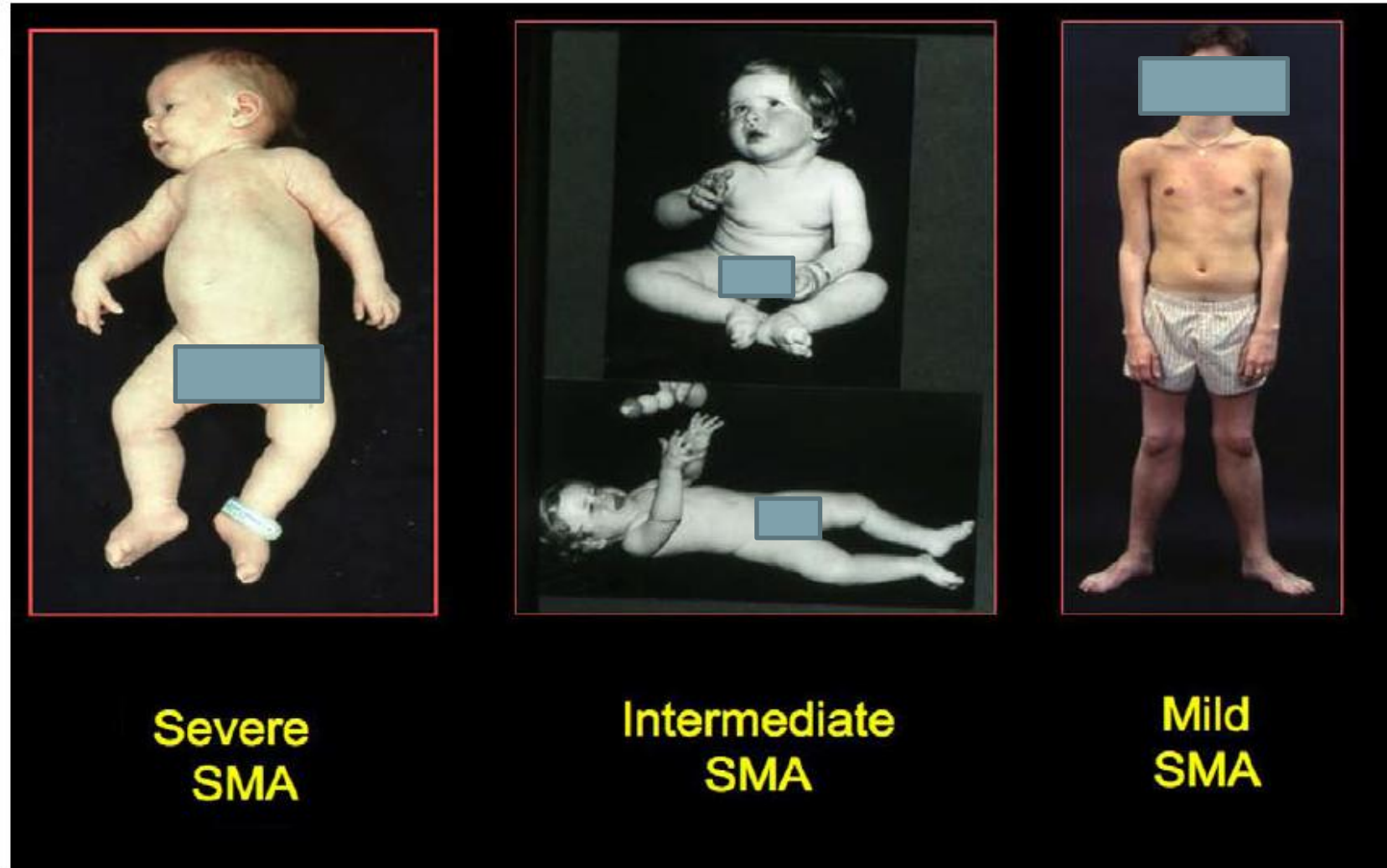
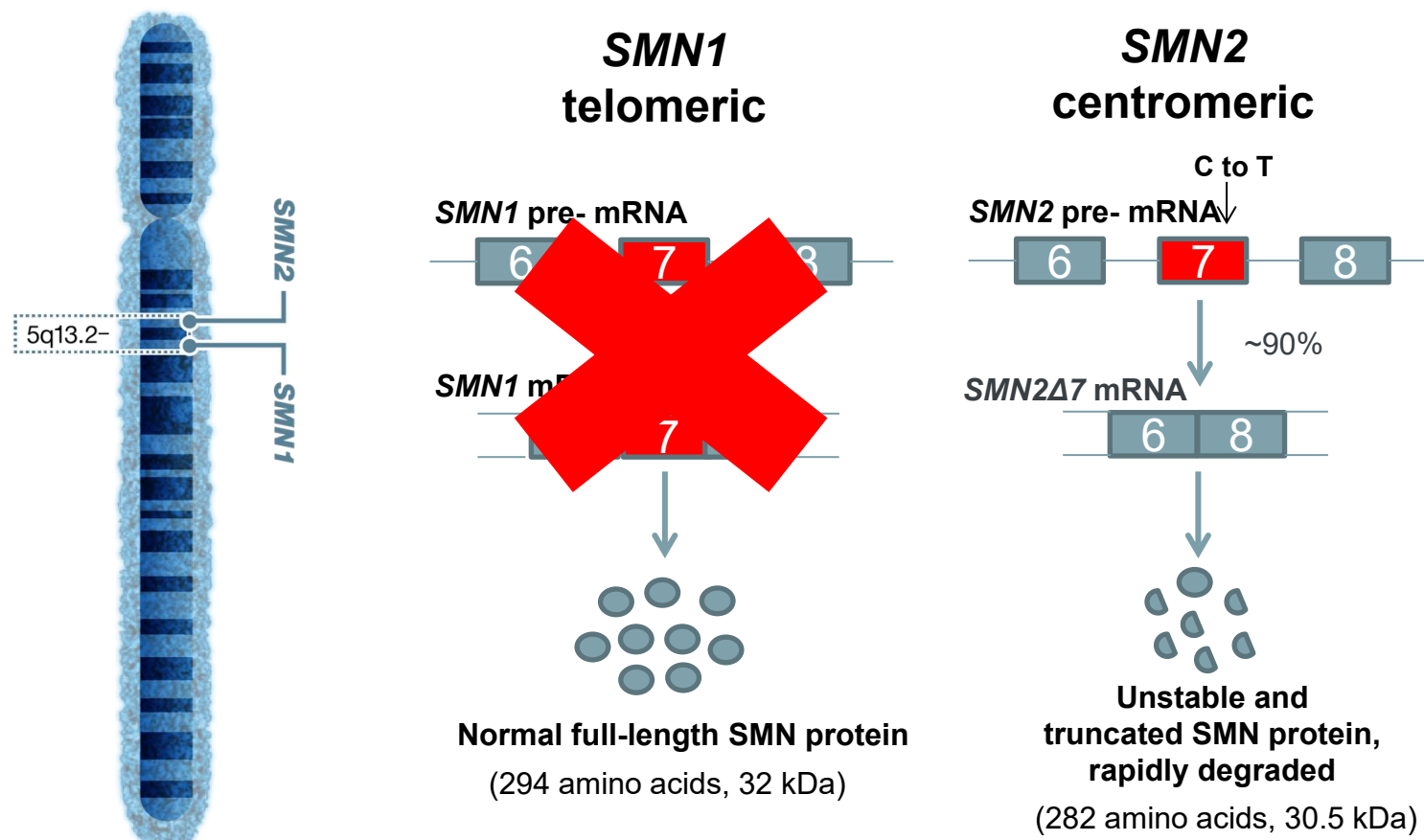


Fig. 1. Three variants of SMA in relation to severity.

SMA monogenic AR disorder (*SMN1* mutations, crom 5q13)



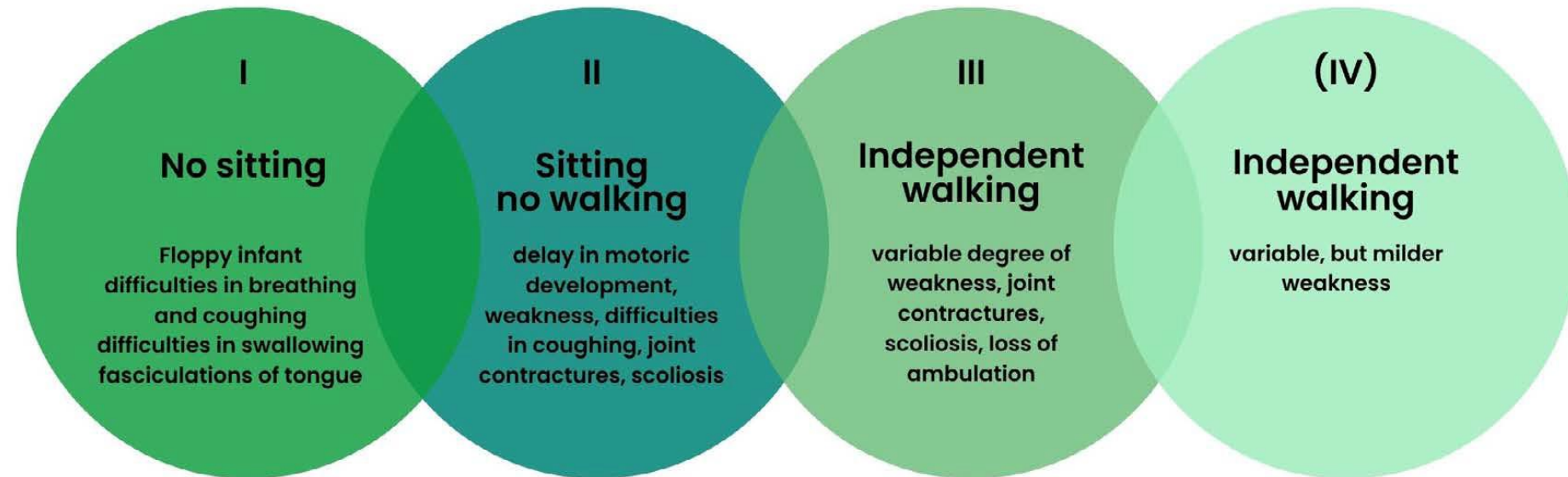
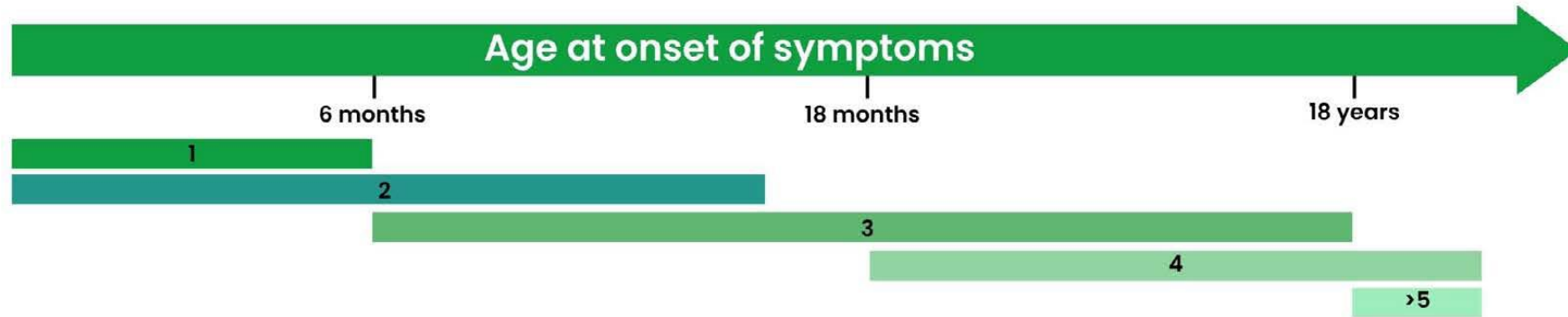
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MILESTONES
ACTION

SMN2 copy
number(s)

SMA Type #

Milestones
Achieved

Clinical
Presentation



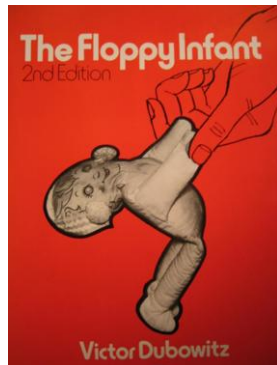
SMA Type I (severe) Werdnig-Hoffman disease



- Severe limb and trunk muscle weakness
- Oro-Bulbar
 - Difficulty feeding
 - Oral secretions swallowing difficulties
 - Failure to thrive
- Respiratory
 - Poor cough
 - Recurrent chest infections



↓ Tone and posture in a neonate ↑



SMA Type II (intermediate)

- Chronic infantile, sitters
- Usually begin between 7 - 18 months

Most common form of SMA:

- Most common manifestation is developmental motor delay
- Infants with SMA type II often have difficulties with sitting independently or failure to stand by 1 year of age

SMA Type II

Disease course

- Scoliosis
- Frequent hip dislocation
- Oro-Bulbar dysfunction
- Malnutrition
- Secondary contractures
- Resp. muscle weakness, nocturnal hypoventilation

SMA Type II disease course



- Musculoskeletal deformities
- The lifespan of patients with SMA type II varies but they are expected to survive into adulthood.
- Respiratory failures occur
- Respiratory infections account for most deaths

SMA Type III Kugelberg-Welander

- 18-36-months-old
- Unsteady gait
- Frequent falls
- Gowers sign
- Muscular fasciculations → impression of tremors (visible when grasping to objects)



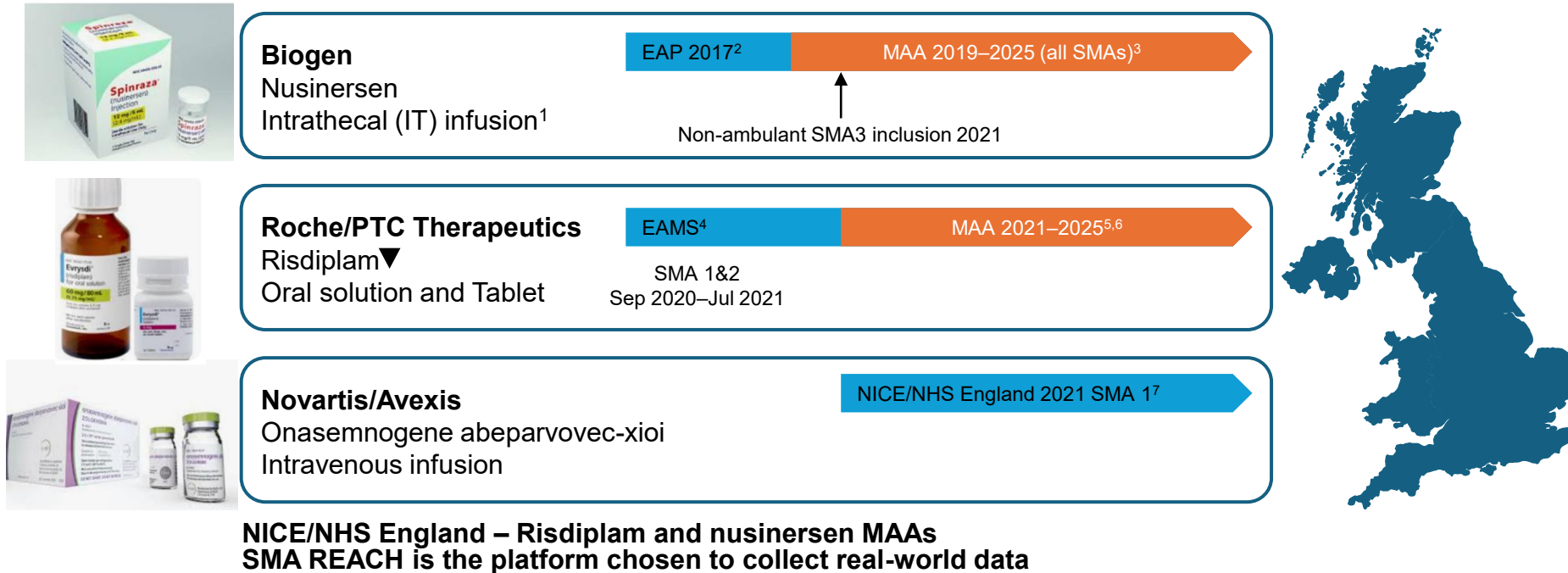
SMA	N=	Probability of walking at 10y after onset	Probability of walking at 40y
<i>Type III a (onset <age 3 years)</i>	195	70%	22%
<i>Type III b (onset >age 3 years)</i>	134	96%	58%

SMA Type III

Disease course

- Slowly progressive proximal weakness.
- Most can stand and walk but have trouble with motor skills (such as going up and down stairs).
- Bulbar dysfunction occurs late in the disease.
- The disease progresses slowly, and the overall course is mild.
- Patients have normal life expectancies.

Current treatments for SMA approved in the UK – SMN enhancing



In the past decade, 3 DMTs that enhance SMN protein expression have been approved by the US FDA and the European EMA

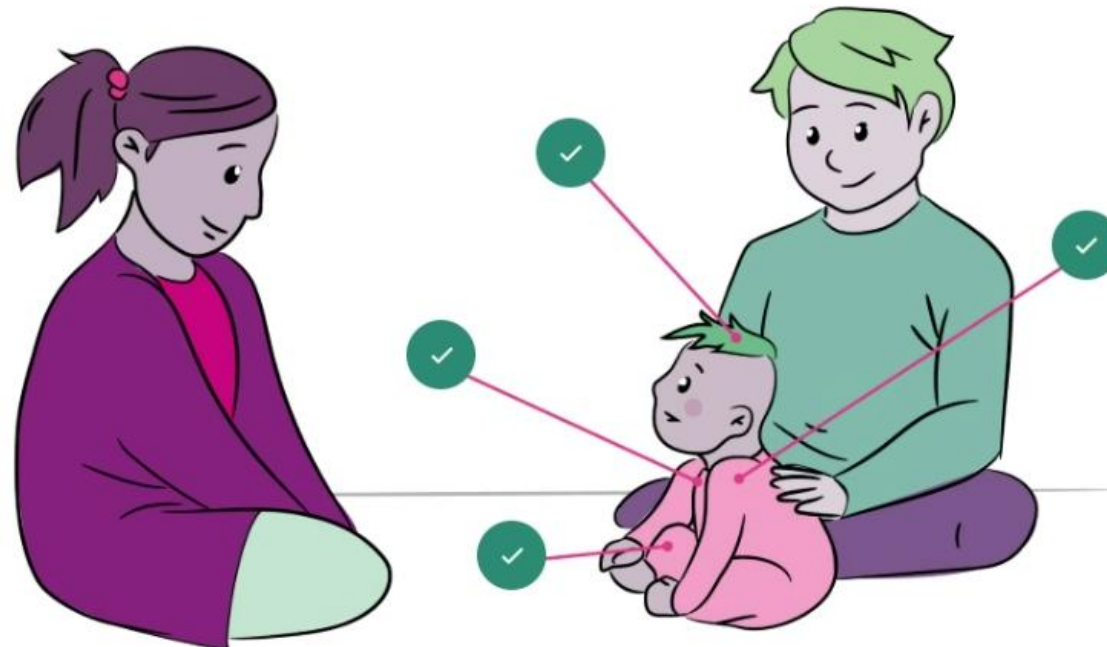
Four Early Signs

4 early signs

5q SMA, damage to the motor neurons can occur in the first few months of life, making early recognition especially important.

Around the age of 3 months, some early signs of 5q SMA may become noticeable.

Select the hotspots to explore the four key signs:



Next speaker



Portia Thorman

Head of Advocacy and
Community, SMA UK



Type your questions as you
think of them during the
presentations

Use the Zoom Q&A function

- **Name of presenter** you would like to answer your question
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Our diagnosis story



Portia Thorman
Head of Advocacy and Community SMA UK



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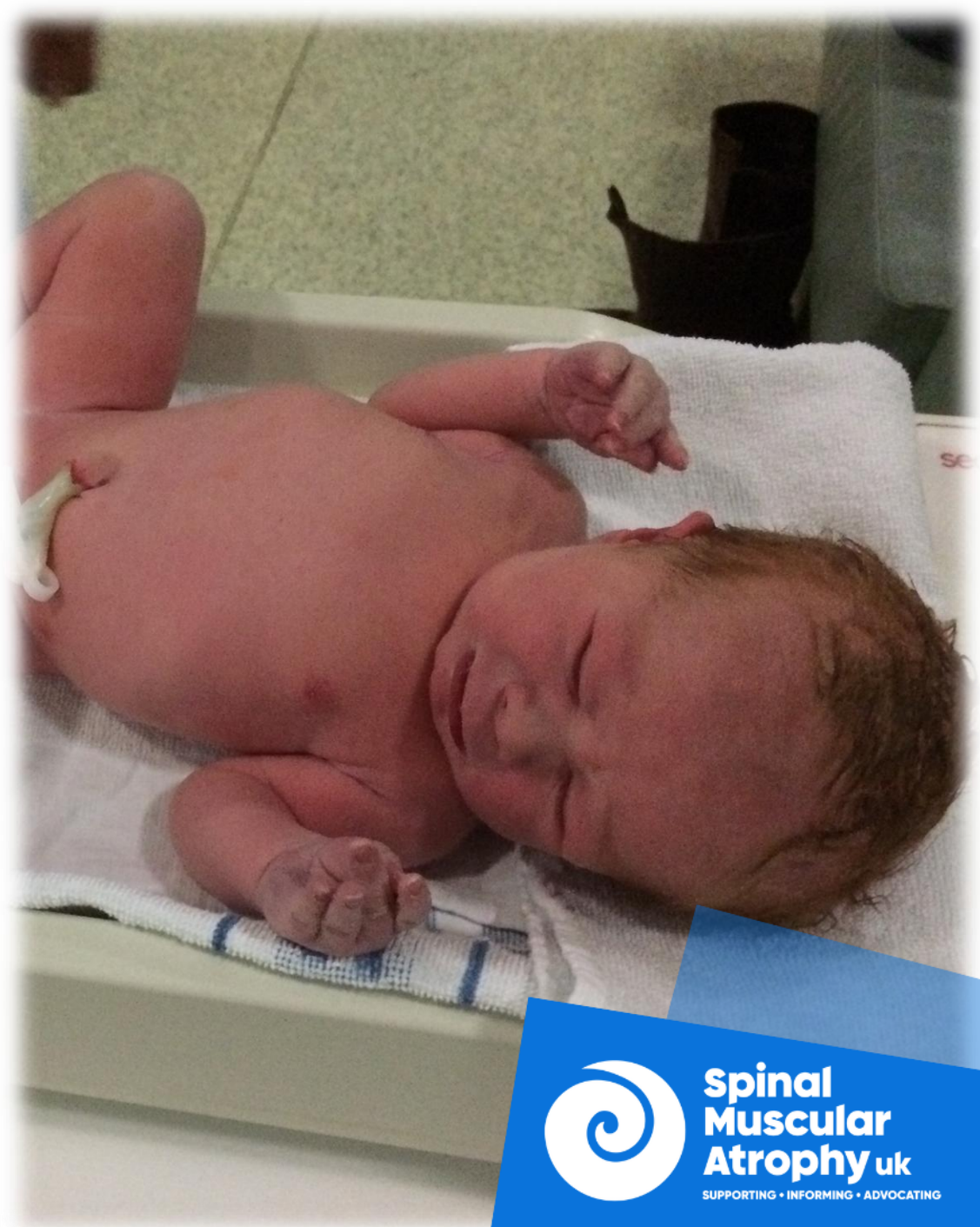
November 2016

- Some difficult scans due to a lack of movement.
- Normal delivery, water birth.
- Required minimal neonatal resuscitation.
- Quiet cry
- Choking on his milk



‘Niggles’ in my mind:

- tummy time
- proportions
- movement
- belly breathing



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5 weeks later:
December 2016



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January – March 2017

- Motor function deteriorated.
- 3 different health visitors
- GP
- Comparing with other babies.



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Three long months in and out of PICU. Adjusting and accepting our 'new norm'.



- Bipap ventilation
- Cough Assist and respiratory physio
- Suctioning
- Enteral feeding
- Specialist seating
- Treatment decisions

April 2017

Treatment initiation at 5 months old whilst in PICU



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Back at home, we started to see progress.



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Thank you for listening!

Questions to: Portia.Thorman@SMAUK.org.uk

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Kathryn Danagher

Health Visitor, North
Tyneside Council



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North
Tyneside
Council

iHV Motor Development Ambassadors: Cascading Awareness and Enhancing Practice

Kathryn Danagher, Health Visitor Team
Lead at Children's Public Health
Service, North Tyneside Council

The role of the health visitor

- With universal reach health visitors and health visiting teams are uniquely placed to identify early signs of concern and respond proactively (Department of Health and Social Care, 2026)
- This is through surveillance, screening and examination (iHV, 2024; Phillipson, 2025 and Department of Health and Social Care, 2026)
- Health visitors can play a valuable role for families by remaining in regular contact with them and offering targeted support, advice and signposting (iHV, 2021)



iHV Motor Development Training:

The session was incredibly informative and equipped Ambassadors to:

- Confidently recognise typical and atypical motor development.
- Understand a range of motor development conditions, including Spinal Muscular Atrophy (SMA), Cerebral Palsy, and Muscular Dystrophy.
- Have sensitive conversations with families about motor development.
- Identify 'red flags', make a high-quality referral, whilst continuing to support families while they await assessment.
- Identify 'amber flags' and support families during the 'watchful wait' period.
- Offer evidence-based advice to promote motor development and high-quality ongoing support.

(iHV, 2025)

North Tyneside Council Motor Development Ambassadors

- Following on from the training, I was asked to lead on the cascade of the awareness session
- Bringing together the fantastic team of Ambassadors, we were able to go through the cascade training materials and the toolkit
- The cascade training materials were **amazing**
- The resources can be used to support information sharing, underpin assessment and, importantly, highlight areas of concern such as 'red flags' in a child's development

Cascade of Awareness Training and Enhancing Practice:

- Across the Children's Public Health Service, North Tyneside Council, we are always focused on innovation and practice development.
- Within three months of completing the Motor Development Ambassador training, the Ambassadors provided cascade training to over 97% of clinical staff; this included our child development practitioners, staff nurses/midwives and health visitors.
- Through iHV corporate membership, staff are able to access the toolkit
- By accessing training with the iHV, our practice can now be enhanced with more robust assessment, meaningful conversations and early intervention.

Auditing the Impact



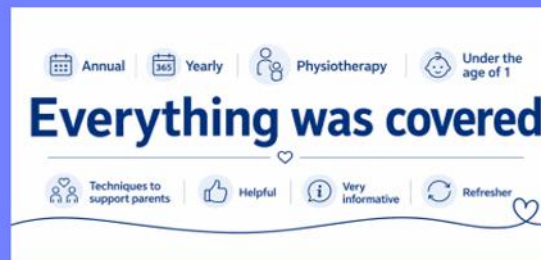
Did the session feel relevant to your practice?



Did you find the learning helpful?

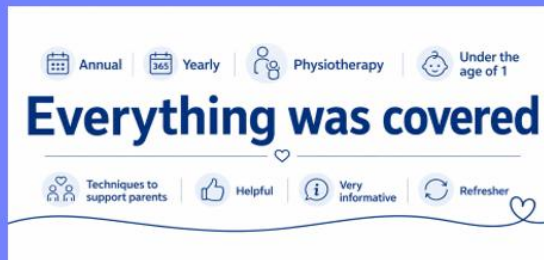


Since the training have you attended the toolkit?



What's next?

- Continuing the role of motor development ambassadors
- Promoting use of the toolkit
- Referral pathways
- Gathering parents' views and experiences
- Further training



References

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- First 1001 Days Movement (2022) Why Health Visitors Matter. Perspectives on a widely valued service. Available at: bit.ly/3QZqy3O
- Institute of Health Visiting (2021) Identifying, referring and supporting infants with Spinal Muscular Atrophy – type 1. Available at: [Identifying, referring and supporting infants with Spinal Muscular Atrophy – type 1 – IHV](#)
- Institute of Health Visiting (2025) What do parents want from a health visiting service? Available at: bit.ly/3JZECp5
- Institute of Health Visiting (2024) Good Practice Points for Health Visitors Supporting Gross Motor Development in Babies and Children Under 5 Years: Part 1, Available at: bit.ly/4dObQaA
- Institute of Health Visiting (2024) Good Practice Points for Health Visitors Supporting Gross Motor Development in Babies and Children Under 5 Years: Part 2, Available at: bit.ly/3wLfzok
- Morton, A. and Wigley, W. (2014) Beyond 'train and hope': Identifying factors that affect implementation of the Promotional Guide in practice. Available at: [Beyond 'train and hope': Identifying factors that affect implementation of the Promotional Guide in practice – Health Visiting](#)
- Phillipson, B (2025) Access to early SEND support through Best Start Family Hubs
- Available at: [Access to early SEND support through Best Start Family Hubs – GOV.UK](#)

Motor Development Ambassadors





Next speaker



Portia Thorman

Head of Advocacy and Community,
SMA UK

Victoria Jackson

Health Visiting Lead - Professional
Services, iHV



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Supporting practice

Lucy de'Lemos, Head of Communications and Fundraising (Spinal Muscular Atrophy UK)
Victoria Jackson, Health Visiting Lead - Professional Services (iHV)

Is your area included in newborn screening for SMA?

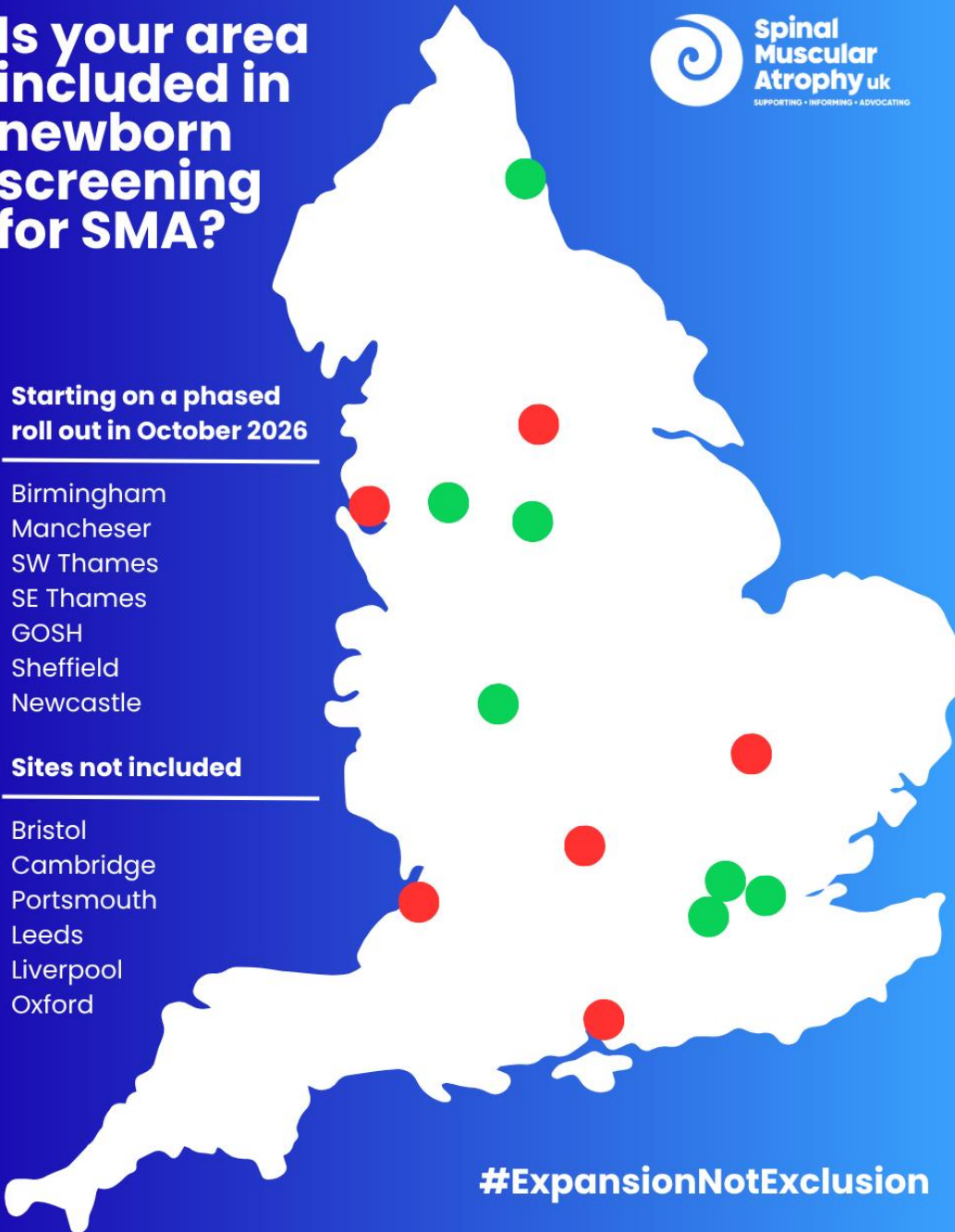


Starting on a phased roll out in October 2026

Birmingham
Manchester
SW Thames
SE Thames
GOSH
Sheffield
Newcastle

Sites not included

Bristol
Cambridge
Portsmouth
Leeds
Liverpool
Oxford



#ExpansionNotExclusion

- March 2026 - Scotland officially added SMA to its newborn screening programme
- Some areas in England have added SMA in their newborn screening
- Not currently offered in Wales or Northern Ireland



Phase one – Now

- Partnership with the iHV focuses on empowering health visiting teams
- Equipping health visiting teams & community practitioners with the knowledge and confidence to recognise early signs of SMA
- Bridging gaps in access to diagnosis, supporting culturally sensitive communication
- Improving opportunity for earlier diagnosis, faster access to treatment, and improved outcomes

Phase two – Next

- Empowering the SMA Community to disseminate resources in their local area to:
 - GP practices
 - Nursery schools
 - Childcare settings

This campaign is funded by Novartis, Biogen and Roche

SMA resources





iHV Spinal Muscular Atrophy (SMA)

This e-learning will focus on 5q SMA, which is the most common form of SMA. When clinicians and families talk about SMA, they are almost always talking about 5q SMA.

The course will equip you with the knowledge and confidence to recognise the signs of 5q SMA and understand the importance of timely referral.

Select the modules to get started:



Module 1: Spotting SMA

DURATION: 20 MINS

Start module 1



Module 2: Taking action

DURATION: 20 MINS

Start module 2



Motor development resources



The collage features several key resources:

- Resources for professionals:** A brochure titled "Resources for professionals" listing topics like "Understanding motor development," "Red flags, and key signs of specific motor development," "Policy, guidance and reports," "Continuing professional development," and "Clinical networks, working groups and pathways." It also includes a section for "SELECT THE EXPANDABLE ACCORDIONS TO FIND OUT MORE:" with a list of topics.
- Resources to support parents and carers:** A brochure titled "Resources to support parents and carers" listing topics like "Supporting parents to understand motor development," "Red flags – when to be worried about motor development," "Condition specific information," and "Advocacy, support and advice." It also includes a section for "SELECT THE EXPANDABLE ACCORDIONS TO FIND OUT MORE:" with a list of topics.
- iHV Institute of Health Visiting LEARN website:** A screenshot of the iHV LEARN website showing the navigation menu (Home, My programmes, All Programmes, About iHV, Get in touch) and the "Motor Development Toolkit" page. The page includes a welcome message and a list of resources.
- Good Practice Points for Health Visitors:** Several brochures titled "Good Practice Points for Health Visitors" covering topics like "Gross Motor Skills Development in babies and children under 5 years: Part 2," "Supporting Gross Motor Development in Babies and Children Under 5 Years: Part 1," "Duchenne Muscular Dystrophy – recognition, diagnosis and clinical care," and "Supporting children with Down syndrome: growth, feeding and development." These brochures include text, images, and diagrams.
- Development E-learning:** A brochure titled "Development E-learning" featuring a colorful geometric design and a list of sections: "Section 1: What is motor development? DURATION: 10 MINS," "Section 2: Ages and stages DURATION: VARIOUS," and "Section 3: Ongoing support DURATION: 25 MINS." It also includes a "Final knowledge checker" section.

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Spot the Signs. Change a Life: The important role of health visiting in early identification of SMA



We will aim to answer as many questions as possible during the live session.

Use the Zoom Q&A function

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- Brief **question**
- **Your name** (if you wish to do so)

Over to you!

Help us to tailor our events to meet **your** needs!

- Submit your anonymised responses to the poll
- What more can we do to support you in your practice?
- Email events@ihv.org.uk with any suggestions



Join us again!



Safer sleep

16 July 2026 – 15:30-16:30

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Future iHV Member Benefit Event Dates



TOPIC	DATE
SEND Special Interest Group	25 June 2026
Research Network	1 July 2026
iHV Corporate Service Leads Network	9 July 2026
Retired Member Network	11 August 2026

All future dates
can be found at:
bit.ly/4enHn2H



iHV Learning and Development

This Mum Moves Ambassadors



23 Jun

Genomics Ambassadors



6/13 Jul

Changing Conversations: Autism and Supporting Behaviour Ambassadors



8 Jul

Practice Assessor, Practice Supervisor



8/9/15 Sep

Safeguarding Supervision Champions



28/29 Sep



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Thank you so much for joining us



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has attended the following 1-hour activity:

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INSTITUTE OF HEALTH VISITING

Date: :

This certificate should be kept within your CPD record and may be used as supporting evidence in revalidation with the Nursing and Midwifery Council.

CEO, Institute of Health Visiting

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Number of hours completed:	
ACTIVITY – What did you undertake? How many hours were participatory? How many hours were individual?	
LEARNING – What were your key insights from the activity?	
INFLUENCE ON PRACTICE – How will I use this knowledge, skill or experience in my practice? What difference will it make to me/ to children, young people, families and communities? Has this knowledge, new skill or experience changed your thinking, if so, in what way?	
FURTHER ACTIONS – What needs to happen for me to use this learning?	
LINK TO NMC CODE (2018) - Which theme or statement does my learning or development support and why?	
LINK TO STANDARDS OF PROFICIENCY (NMC, 2022) - Please identify the part or parts of the relevant standards that you used to inform your CPD	
ANYTHING ELSE TO NOTE:	

For further information, please access: <http://revalidation.nmc.org.uk/>

Continue your CPD!

After this event you will be able to access the following resources on the iHV website:

- A recording of this live session (no recording on other devices is allowed)
- This slide set
- Links and background reading
- A link to download a Record of Attendance & reflection template

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