# SMA Highlights: Updates from

# Biogen.

Dear SMA Community,

It's hard to believe we are approaching the home stretch of 2022. But it's so wonderful to reflect on what we've experienced together so far. Highlights include engaging with an advisory board of adults at the Cure SMA Conference, which challenged us to think about how we show up for adults with SMA in our programming and content.

Biogen invited two adults with SMA to speak with us to further our understanding of what living with a disability means to them. We are committed to help educate the public to help raise awareness about SMA. Follow our social channels for more to come. Through these efforts, we celebrate our connections with the community – as they are truly the inspiration for all we do.

We are still actively recruiting for our **DEVOTE**, **RESPOND** and **ASCEND** clinical trials. We encourage you to learn more about these studies at clinicaltrials.gov.

- The Biogen Team

## **Clinical Trial Spotlight**

**DEVOTE**: A Phase 2/3 study evaluating the safety and effectiveness of different investigational doses of nusinersen in Parts A, B and C **We continue to enroll participants into DEVOTE at 7 sites in the US.**\*

#### **SMA Patient Stories**



Alexa is an entertainment lawyer for a Hollywood production company, helping child performers navigate the industry. Her SMA has shaped who she is today: optimistic, courageous and determined.

Click to read Alexa's story.

## **SMA Clinical Program Status\***

**DEVOTE**: Phase 2/3, Part B; enrolling at 7 US sites:

- Stanford Hospital and Clinics (CA)
- Children's Hospital Colorado (CO)
- Ann & Robert H. Lurie Children's Hospital of Chicago (IL)

<u>RESPOND</u>: Phase 4; enrolling at 12 US sites:

- Arkansas Children's Hospital (AR)
- Stanford Neuromuscular Research (CA)
- Children's Hospital Colorado (CO)
- Nemours Children's Hospital (FL)

ASCEND: Phase 3b; enrolling at 6 US sites:

- Arkansas Children's Hospital (AR)
- Rare Disease Research, LLC (GA)
- University of Iowa Children's Hospital (IA)
- Boston Children's Hospital (MA)

- The Johns Hopkins Hospital (MD)
- Boston's Children's Hospital (MA)
- St. Jude Children's Research Hospital (TN)
- The University of Texas Southwestern Medical Center (TX)
- Rare Disease Research, LLC (GA)
- Ann & Robert H. Lurie Children's Hospital of Chicago (IL)
- Children's Specialty Healthcare (MN)
- Washington University School of Medicine (MO)
- Oregon Health and Science University (OR)
- Children's Hospital Philadelphia Neurology (PA)
- University of Utah, Primary Children's Hospital (UT)
- Children's Hospital of The King's Daughters (VA)

- Atrium Health Wake Forest Baptist (NC)
- Children's Hospital of The King's Daughters (VA)

\*As of October 12. 2022

#### **INDICATION**

SPINRAZA® (nusinersen) is a prescription medicine used to treat spinal muscular atrophy (SMA) in pediatric and adult patients.

#### **IMPORTANT SAFETY INFORMATION**

**Increased risk of bleeding complications** has been observed after administration of similar medicines. Your healthcare provider should perform blood tests before you start treatment with SPINRAZA and before each dose to monitor for signs of these risks. Seek medical attention if unexpected bleeding occurs.

Increased risk of kidney damage, including potentially fatal acute inflammation of the kidney, has been observed after administration of similar medicines. Your healthcare provider should perform urine testing before you start treatment with SPINRAZA and before each dose to monitor for signs of this risk.

The most common side effects of SPINRAZA include lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome.

These are not all of the possible side effects of SPINRAZA. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Before taking SPINRAZA, tell your healthcare provider if you are pregnant or plan to become pregnant.

Click here to access full Prescribing Information.

This information is not intended to replace discussions with your healthcare provider.