SPINRAZA (nusinersen) 12 mg solution for injection

Around 6,600 patients suffering from SMA are now being treated with Spinraza (nusinersen) worldwide[1]

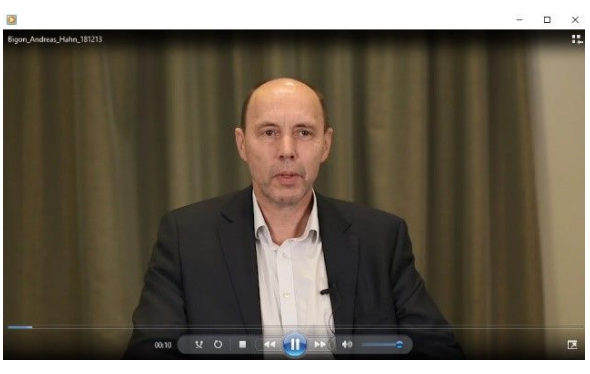
Patient and/or caregiver have given consent to publish the picture

SMA, being the leading genetic cause of mortality in infants and toddlers[2], got the first ever treatment impacting the progression of the disease when Spinraza (nusinersen) was approved on the 30th of May 2017[3], and now has reimbursement for selected patients across all Nordic countries.

Growing experience using Spinraza in the treatment of older patients

In a growing number of countries, Spinraza (nusinersen) is funded to be used according to the European label[4], which means that the clinicians there have a growing experience from treating also older patients with SMA.

In this newsletter you will find a short film with Professor Andreas Hahn, who is a senior consultant and deputy director of the Department of Paediatric Neurology at the University Hospital in Gießen in Germany. He spoke at the LIS-N & LER-N meeting in December 2018 about his experience from treating patients of different ages and different types of SMA with Spinraza (nusinersen) since January 2017.



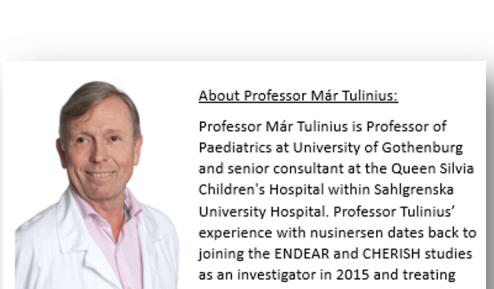
Nordic multidisciplinary educational event – LIS-N & LER-N

At the second LIS-N & LER-N meeting held in Stockholm in December last year, professor A. Hahn, together with several Nordic key medical experts on the management of SMA, presented and discussed different topics such as the reimbursement status across the Nordic countries, data on Spinraza (nusinersen) and the clinical experiences and challenges treating older patients, for ex. patients with complex spines.

If you are interested in reading a report with a summary of the presentations from the meeting you can download a pdf of the report here.

Upcoming webinar focusing on the basics of SMA, and pivotal trials for Spinraza (nusinersen)

If you would like to know more about SMA and the cause of the disease, the natural history for the different phenotypes and the basic understanding of the benefit and risk of the treatment with Spinraza (nusinersen), you will be able to join a webinar on the 9th of May, where professor Már Tulinius will give a presentation. You will also be able to ask questions to professor M. Tulinius at the webinar.



Invitation to the webinar will be shared separately.

togetherinsma.com

References

1. http://investors.biogen.com/static-files/c0d4fbe2-d4f2-404b-be17-19e770386d6e
2. Lunn MR & Wang CH. Lancet. 2008;371(9630):2120-2133
3. SmPC nusinersen
4. SmPC nusinersen

Please, click here to see Spinraza product information

Precautions

Patients with profound hypotonia and respiratory failure at birth, where Spinraza has not been studied, may not experience a clinically meaningful benefit due to severe SMN protein deficiency. There is a risk of adverse reactions occurring as part of the lumbar puncture (e.g headache, back pain, vomiting; see section 4.8 in the SPC. Potential difficulties with the route of administration may be seen in very young patients and those with scoliosis.

Thrombocytopenia, coagulation abnormalities, including acute severe thrombocytopenia and renal toxicity have been observed after administration of other subcutaneously or intravenously administered antisense oligonucleotides. If clinically indicated, platelet, coagulation and urine protein laboratory testing is recommended prior to administration of Spinraza.

There have been reports of communicating hydrocephalus. See section 4.4 in the SPC for further details.

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