PALVELUVALIKOIMA
Tjänsteutbudet | Choices in health care

SUMMARY 4 February 2022

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UPDATED RECOMMENDATION ON NUSINERSEN IN THE TREATMENT OF SMA

At its meeting of 4 February 2022, the Council for Choices in Health Care in Finland (CO-HERE Finland) adopted an updated recommendation on nusinersen in the treatment of SMA. The recommendation replaces the previous recommendations approved by CO-HERE on 15.3.2018 and 4.9.2019 concerning nusinersen treatment.

Nusinersen is indicated for the treatment of spinal muscular atrophy (SMA). Nusinersen does not cure the disease itself, but it can stop the progression of the disease. Nusinersen is administered by lumbar puncture into the cerebrospinal fluid.

According to the recommendation, nusinersen is part of the service choices in healthcare under the following conditions:

New diagnosed SMA1 or SMA2 patients

- The patient has been clinically and genetically diagnosed with SMA1 or SMA2.
- The patient is not in need of permanent respiratory support or there is no other medical impediment to treatment.

Treatment-experienced patients with SMA1 and SMA2

- The patient is not in need of permanent respiratory support or there is no other medical impediment to treatment and the criteria for further treatment are met.
- Treatment may be continued at the age of 18 years if the criteria for further treatment are met.

SMA3 patients

- SMA3 patients under 18 years of age with onset of symptoms in childhood, with a genetically diagnosed disease that is progressing rapidly (for example, a decrease in the HFMS score of at least 3 points per year). The effectiveness of the treatment should be assessed after one year of treatment.

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In addition, a very significant price reduction on the current price is required.

Criteria for continued treatment

The effects of treatment should be assessed annually. Before starting treatment, the possibility of a change brought about by the medicine should be assessed, taking into account the patient's functional capacity and structural limitations. During the first year of treatment, an objectively confirmed and clearly improved clinically meaningful response to treatment with improvement in ability to function should be achieved. Later continued response to treatment is a minimum requirement for the continuation of treatment to be medically justified.

COHERE Finland recommends that a joint working group of paediatric neurologists and adult neurologists develop a harmonised assessment description for ability to function based on validated and objective indicators, which will be used in the future to monitor the effectiveness of treatment and to decide whether to continue treatment. Particular attention should be paid to how to define criteria for effective treatment for individual treatment decisions in this heterogeneous population. In addition, COHERE Finland recommends the introduction of a quality-of-life indicator.

Spinal muscular atrophy (SMA) is a rare hereditary neuromuscular disease in which muscles do not receive signals from damaged nerve cells in the spinal cord. There are several subgroups of SMA, which are defined by the number of copies of the SMA2 gene, the clinical picture and the morbidity age.

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This is a summary of a recommendation adopted by the Council for Choices in Health Care in Finland (COHERE Finland). The actual recommendation and the related background material are available in Finnish on the website of COHERE Finland under Recommendations.

The summary of the recommendation is also available in Swedish and Finnish on the website.

The Council for Choices in Health Care in Finland (COHERE Finland) works in conjunction with the Ministry of Social Affairs and Health, and its task is to issue recommendations on services that should be included in the range of public health services. Further information about service choices in healthcare is available on the COHERE Finland website.

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