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Outcome of joint negotiations for Zolgensma

Belgium, Ireland and the Netherlands have reached an agreement on the pricing of Zolgensma, a gene therapy for the treatment of Spinal Muscular Atrophy (SMA). Zolgensma will be reimbursed for two specific groups of young patients in all three countries.

The aim of the Beneluxa Initiative is to enhance the access of patients to high quality and affordable treatment. The joint reimbursement process for Zolgensma started with a Health Technology Assessment by Belgium, Ireland and the Netherlands, with Austria as external reviewer in the Belgian procedure. In July 2021 the three directly participating countries initiated price negotiations.

It is the first time that Belgium, Ireland and the Netherlands have jointly reached an agreement on the price of a drug. While previous Beneluxa pilots have already proven that joint negotiations with two countries can be effective, the process for Zolgensma shows that negotiations by three countries can also be successful. As a result, the gene therapy will be available in all three countries for SMA patients with a bi-allelic mutation in the SMN1 gene and a clinical diagnosis of Type 1 and for presymptomatic patients with up to three copies of the SMN2 gene.

Frank Vandenbroucke, the Belgian Minister of Health and Social Affairs:

“Beneluxa is still called an Initiative, but is in the meanwhile a strong ‘brand’ and gold standard for voluntary collaborations between Member States. Our ability to make Zolgensma affordable for SMA patients in our three countries simultaneously shows that Beneluxa’s stated aim to ensure sustainable access to innovative medicines can be translated into tangible and shared results.”

Paul Blokhuis, the Dutch State Secretary for Health, Welfare and Sport:

“Great that the collaboration between the countries is such a success. This partnership makes medicine more accessible and this is great news for the patients who now get access to this medicine. We are committed to continuing this successful collaboration in the future.”

Stephen Donnelly, the Irish Minister for Health:

“The reimbursement of Zolgensma by the HSE represents a great achievement in ensuring access to this gene therapy for two groups of young SMA patients. This is a welcome decision for their families, carers and friends. The success of the joint process for Zolgensma represents a tangible output of the Beneluxa partnership and I wish to take the opportunity to recognise and thank the HSE, including the National Centre for Pharmacoeconomics, and the other participating countries for their significant role in this process.”

Paul Reid, the Irish HSE Chief Executive Officer:

“The HSE as its standard, engages in commercial negotiations with drug manufacturers to ensure we obtain the best possible value for new medicines. This enables the HSE to reimburse as many medicines as possible, for as many patients as possible, within its resources. HSE decisions on which medicines are reimbursed by the taxpayer must be made on objective, scientific and economic grounds. Providing funding for new high-cost innovative medicines alongside the many demands of the health service presents a continual challenge and the Beneluxa engagement with international colleagues aims to collectively address this challenge. This is the first time that Belgium, Ireland and the Netherlands have jointly conducted such a negotiation and reached an agreement on the price of a medicine. From today, the HSE will provide reimbursement of Zolgensma for a subgroup of patients who meet the specified criteria on which the Beneluxa assessment and negotiation was based.”

Beneluxa achievements

In 2015 the Beneluxa cooperation was initiated with the aim of sustainable access to and appropriate use of medicines. Together, Belgium, the Netherlands, Luxembourg, Austria and Ireland want to enhance patients' access to high quality and affordable pharmaceutical treatments. Besides undertaking joint price negotiations, the partnership works together on horizon scanning, health technology assessments and sharing of knowledge and expertise on policies and challenges yet to come.

Recently, the International Horizon Scanning Initiative (IHSI) has been launched, having originated within the Beneluxa collaboration. Its goal is to build a permanent horizon scanning system that can support countries and institutions in policy planning and their decision making regarding the reimbursement of new pharmaceuticals. A wide group of countries is currently invested in the IHSI.

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(<https://www.health.belgium.be/>)



Ministry of Health, Welfare and Sport

(<https://www.government.nl/ministries/ministry-of-health-welfare-and-sport/>)



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