

Biogen Europe
Attn: Dr. W. Schmidt, President Biogen Europe

Per e-mail:

Date 18 June 2026

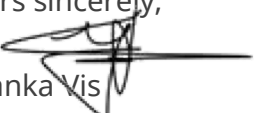
Subject Urgent need for access to omaveloxolone in the Netherlands

Dear Dr. Schmidt,

We kindly ask your attention regarding ongoing price negotiations concerning omaveloxolon (Skyclarys®) for Friedreich ataxia, a progressive and severely life-shortening disease. We previously raised this matter with Ms Jennifer Papandreou, General Manager of Biogen Benelux, who responded by stating that Biogen is making significant efforts and applying innovative thinking and that proposals are currently being discussed. However, no concrete breakthrough has yet been achieved. Unfortunately, Dutch patients can't wait any longer as every delay results in irreversible loss: a teenager will gradually lose her ability to speak, a young adult is forced to stop working and a parent must watch, knowing that a potentially beneficial treatment for their child is available only in neighbouring countries.

We understand that pricing and reimbursement negotiations are complex and involve many considerations. Yet in our country it is ultimately a very small group of patients who bear the consequences of prolonged delays: people with no alternative treatment options for whom every month matters. We therefore respectfully urge you to personally support efforts helping to reach a solution, together with the Dutch Ministry of Health, to whom we will also be addressing this concern. Potential approaches could include an early access-arrangement, a pay-for-performance price model, or price reductions following the period of market exclusivity. We trust that you will make every effort within your sphere of influence to ensure that Dutch patients can gain access to omaveloxone as soon as possible.

Yours sincerely,



Jovanka Vis
Director Spierziekten Nederland