

Nicole Gusset
SMA Europe
Via: secretariat@sma-europe.eu

Date: December 8th, 2023
Subject: Your support in asking Roche to come to agreements with the Dutch government

Dear SMA Europe,

With this letter we kindly ask your much needed support.

Most adult SMA patients in the Netherlands have access to any of the new medications Evrysdi™ or Spinraza™. Yet, a small, not to be neglected group of patients is still waiting on ongoing procedures and negotiations between pharmaceutical company Roche and our government, possibly facing nonacceptance. This comprises patients 26 years of age and older, who are physically unable to receive an epidural (and thus Spinraza). We don't need to convince you of the urgency of them receiving Evrysdi as soon as possible. Every day that passes, they continue to decline and lose motor abilities, possibly very unnecessarily.

Both Evrysdi and Spinraza are covered by the Dutch health insurance for young patients up to, respectively, 25 and 9.5 years of age. For older children and adults, access to Spinraza is provided by means of a so-called conditional approval: a research trajectory organized in agreement with the Dutch government and the pharmaceutical company of play (Biogen). In this trajectory patients can choose to participate, receiving treatment while additional data on medicine efficacy is collected. Roche and the Dutch government are willing to make similar arrangements with regards to Evrysdi. However price negotiations seem to be extremely cumbersome. After months of negotiating, Roche Netherlands has recently asked the government and their own headquarters to speak to each other directly. A meeting is scheduled next week on December, 12th.

Will you please join us in our appeal and ask Roche headquarters before the scheduled meeting to come to an agreement with our government, thereby giving all Dutch SMA patients a chance to at least try any of the available treatments? In many European countries people like those in the group we described already do have access, but our group still misses out. This is unexplainable as well as unacceptable to our patients, us and surely also to you.

Kind regards,

Marcel Timmen,
Managing director, Spierziekten Nederland

