Patient Information Letter – MS Quality Registry

Dear Sir/Madam,

To provide the best possible care for people with multiple sclerosis (MS), neurologists across the Netherlands work closely together. To further improve treatment, it is important to gain a better understanding of how MS progresses and how different treatments affect patients. For this reason, the Neurology Registry Foundation (Stichting Registratie Neurologie, SRN) has established the MS Quality Registry.

This registry collects information about the treatment and care of people with MS in the Netherlands. The MS Quality Registry was developed by the Neurology Registry Foundation in collaboration with the Multiple Sclerosis Society Netherlands (Multiple Sclerose Vereniging Nederland, MSVN), with the aim of improving the quality of care for people living with MS.

Why is there an MS Quality Registry?
MS is a complex disease for which there is no single standard treatment. A range of medications and treatment approaches are available, and not every treatment works equally well for every patient. By collecting information on treatments and their outcomes in a nationwide registry, doctors and researchers can better understand which treatments are most effective. This knowledge helps improve care for groups of patients and can also contribute to more personalized care for you as an individual patient.

Protection of your personal data
Medical information related to your MS will be included in the central MS Quality Registry. Protecting your privacy is very important to us. Therefore, your personal data are pseudonymised before being entered into the registry. This means that your information is assigned a unique code and cannot be directly traced back to you.

Only your treating neurologist and the healthcare professionals directly involved in your care have access to your identifiable medical records. Data in the registry are stored and processed securely in accordance with applicable privacy and data protection legislation.

Voluntary participation
Participation in the MS Quality Registry is voluntary. You have the right to decide, at any time and without giving a reason, that your hospital may not submit your data to the registry. If you choose to opt out, your data will no longer be included in the registry and will not be used in future analyses.

You can arrange this through your neurologist or MS nurse. They can also provide you with more information about the MS Quality Registry.

More information
For more information, please visit the MS Quality Registry website. There you will also find the Privacy Statement, which explains how patient data are collected, stored, and used within the registry.