

A study comparing the care of patients in France, Netherlands, Belgium, and Spain is enrolling patients.

We aim to streamline medication and surgical treatment for Marfan syndrome across Europe by developing European guidelines. However, current guidelines deliberately leave room for interpretation. For example, one might prescribe a beta-blocker or an angiotensin II receptor blocker to slow down the rate of aortic dilatation, as no evidence currently exists to show the superiority of one option over the other, or the combination of both. Similarly, the choice of surgical technique for performing an aortic root replacement is left to the experience and preference of the surgeon. The guidelines only provide advice on which patients require surgery.

Thus, in clinical practice, different treatment strategies may be used for similar patients. In this study, we investigate how Marfan patients in France, the Netherlands, Belgium, and Spain have been treated in clinical practice over the past few decades. We aim to create an overview of what medication was prescribed, when, and for how long. Furthermore, we will study when and why patients were admitted to the hospital, if they required aortic surgery, and whether they suffered from any complications. Lastly, we will assess when and how many patients experienced aortic dissection.

Using this data, we can evaluate treatment practices across parts of Europe. Additionally, this study allows us to identify any structural differences in treatment strategies both between and within countries. Finally, we can evaluate whether a relationship exists between different treatment strategies and the occurrence of aortic events.