

Event the 29th of June, 2022, Rare election 2022 – a Swedish regional activity during ECRD 2022.

## Summary

**Healthcare for people living with rare diseases (PLWRD) in Sweden is as organized as a symphony orchestra without a conductor – to improve it, a holistic approach with tact and intuition is needed**

**Swedish parliamentary politicians in a debate about rare diseases and their calls for action**

The need for more coordination of healthcare for PLWRD, both nationally and between Sweden's 21 regions, was often mentioned in Rare Diseases Sweden's election debate.

On 29 June 2022, Rare diseases Sweden took the opportunity to invite politicians from all eight parliamentary parties for a "*Rare debate*", in connection with the European conference ECRD 2022.

The President of Rare diseases Sweden, Caroline Åkerhielm, opened with a description of the current situation in Sweden: "We must get away from regional thinking, we need a national plan for rare diseases".

The representative of the Center Party agreed that Sweden's 21 regions are too small to handle rare diseases on their own. The current situation in the rare area was described as a symphony orchestra without a conductor, where no one holds the rare baton.

The moderator, Mr Sandro Wennberg, asked for the politicians' estimation: "Do you see a red, green or yellow light for implementing measures in politics that improve the situation of people with rare health conditions?" Yellow became a common answer. Lina Nordquist from the Liberal Party, emphasized that there is broad support for improvements, but that the Social Democrats (the party in government position) does not want a national strategy for rare health conditions. She continued: "We have to have a strategy; we cannot dabble. Away with the handbrake!"

Eva Olofsson, representing the Left Party, did not think it was possible to give the green light yet: "Health care does not address equality."

Acko Ankarberg Johansson (the Christian Democrats) answered yellow, with the motivation "nothing happens, there must be a change for real". She added that there is too much control of care and too little follow-up.

The representative for the Conservatives Marie-Louise Hänel Sandström, also gave the yellow light and advocated more coordination in primary care and more equal care throughout the country. Furthermore, all politicians emphasized the importance of listening to patients.

Most politicians were appalled by the figures in Rare Diseases Sweden's latest membership survey, where three out of ten stated that they had been denied care for simple conditions, due to their rare state of health. Furthermore, the clear picture that not having a diagnosis limits access to health care and treatment dramatically. For more information, see [Rare Diseases Sweden's poster #219 at ECRD](#). Margareta Fransson, the Green Party, emphasized the importance of a good treatment in healthcare, as well as daring to think outside the box when it comes to rare health conditions.

The liberal Lina Nordquist commented that the changes must be made within the current care structure.

Eva Olofsson (Left) emphasized the lack of continuity, the care staff has too little time for both patients and collaboration with other professions in care.

The other moderator, Mr Marco Morner, wondered why improvements in the rare field are so slow.

Anders W Jonsson (C) replied that it is important to dare making difficult decisions.

“It can also be challenging to implement decisions,” replied Lina Nordquist (L), who called for something she described as “a holistic approach with piano fingers”. She illustrated that bringing together everything that is needed is required in order to reach any improvement. The decisions must also be followed up, to see how it turned out in practice.

In a breakout session, politicians and participants were divided into two groups and politicians got the task to agree on proposals for action: Find a bottom level – what measures can we agree on to improve the situation for those who live with rare health conditions? Anders W Jonsson (C) emphasized that the problem is already well defined, therefore it is a matter of remedying the problems that have long been established. He said that three things must be resolved:

- **Local coordination**
- **National coordination**
- **The issue of orphan drugs, precision medicine and new treatments**

But how do we get there? Dig where you stand, don't invent another wheel, and develop tools on a national level, urged Mikael Dahlgvist (the Social Democrats).

Lina Nordquist (L) suggested that an authority should bear main responsibility, for example the National Board of Health and Welfare, but that many other authorities also need a clear mandate to collaborate and become involved in the work.

"Do not forget dental care", commented Caroline Åkerhielm.

### **The cancer strategy model**

The Swedish National Cancer Strategy is sometimes mentioned as a model for solving even the rare problems, preferably with extra allocation of resources. This was seen as especially important in the initial stage, where changes need to happen to get started.

Important points that also were mentioned are the need for further training for healthcare professionals on rare diagnoses and time to listen to patients and their relatives and to acquire knowledge about the diagnoses.

### **Important to move forward**

There was a consensus on the importance of moving forward with this important work. Or as the representative of the Green Party put it: “I do not want a repeat of the same discussion again in a few years.”

However, the discussion during the election debate on 29 June 2022 could just as easily have taken place 10-15 years ago, with basically the same starting points, arguments, opinions and proposals for action. Our hope, however, is that the current decision-makers can finally achieve the improvements that the Swedish National Association of Rare diseases has advocated for almost 25 years, with a national strategy for rare diseases, both as a guiding star and a cornerstone for the continued work.