

CREATION OF NATIONAL NETWORKS OF CENTERS OF EXPERTISE IN THE NL

VASCERN

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Activity	Creation of a National Network of Centers of Expertise by Hevas and collaboration with the Dutch National Alliance for Rare Diseases (VSOP) in the Project Connect Extended
Area	Communication and Dissemination, Governance
Duration	2019/2020
Contact	Caroline van den Bosch Hevas and VASCERN, Maria Jongma Hevas, Eric Vermeulen VSOP

1. SUMMARY

i The Dutch Patient Alliance for Rare and Genetic Diseases (VSOP) started in 2019 a project pilot called **Project Connect Extended**¹ which gathers in the Netherlands 26 centres of expertise, 11 patient organisations and represent 16 rare diseases. The project, funded by the Association of health insurers, has the objective to increase the collaboration in the Netherlands between centers of expertise, patients and care providers as well as to facilitate their interaction in the field of care and research.

Hevas, the Dutch umbrella patient organisation for vascular anomalies, was given the opportunity to join this project together with other 4 Dutch centers of expertise specialized on vascular anomalies. One of these 4 centers is a Full Member of the VASCA Working group within VASCERN, the ERN that focuses on Vascular Anomalies.

All together they are now building a common website of centers of expertise. The creation of this common website is a product of a broader strategic plan of the VSOP to stimulate the development of National Networks of Centers of Expertise, and to foster the integration of the ERNs at national level. One of the main goals of the Dutch National Alliance is now to create National Networks of the national centers of expertise and to foster a solid and continuous collaboration with the ERN Healthcare provider centers.

¹ <https://ibmexpertisecentrum.nl/over-het-expertisecentrum/>

2. INITIAL SITUATION

i Hevas already started 10 years ago to bring the 4 Dutch Centers of expertise on Vascular Anomalies together by organizing meetings and seeking collaboration during medical conferences. Hevas started formally to organize these network meetings on a regular basis since early 2019, without the participation of VSOP, in both face to face meetings and conference calls. Since a year ago, the group has been established and formally called the National Network of Centers of Expertise for vascular anomalies.

In parallel, Hevas that is also active in the VASCA Working group within the ERN VASCERN, was invited to participate in the Project Connect Extended driven by VSOP in order to encourage the centers to formally create a Network at national level. VSOP has developed this pilot with a group of centers specialized in rare muscular diseases.. In March 2020, Hevas and VSOP discussed on a rough concept of the common website that is now under construction. The creation of this National Network will help not only the patients and their families find out the right expertise in the right hospital but it will also be helpful for the next round of the national evaluation of the National Centers of Expertise to be performed by the Dutch Government in 2020.

3. CONTRIBUTION TO PATIENT ENGAGEMENT AND/OR IMPROVEMENT OF CARE

i The Project Connect Extended contributes **to increase the visibility of all the healthcare centers of expertise** that is essential for the patients living with a rare condition, their relatives and care providers. Moreover, **it strengthens cooperation** not only between the patient organisations and centres of expertise, but also between the centres of expertise themselves.

The digital communication platform used for this purpose, a multisite, will contribute **to build the legitimacy of these centers of expertise at national level**. The fact that they are recognized “centers of excellence” by the national authorities, and that some of them collaborate in VASCERN, will increase the degree of confidence in the patient community and in the public in general.

The creation of a common website for all the centers for vascular anomalies will also **enhance a timely access of information for the patients and their families**. It will be more easy for them to find the right hospital in the Netherlands. They will also be able to find basic information on vascular anomalies, to find the right treatment and to identify and contact the medical team involved.

Together with the VSOP and the centers involved, Hevas already participated in the selection of the information to be included in this website. **They brought their views as patient organization and they provided concrete information on the disease, the burden of the disease and the treatments**. All this published information will be commonly provided and revised regularly by all the participating centers and patient organisations.

4. SUCCESS FACTORS

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- The Project Connect Extended has proven to be **a good instrument to enhance a successful collaboration** in particular between the 4 centers of expertise in VASCA. The previous collaboration between Hevas and the centers of expertise is also part of the success.

- In this context, the centers have started to share more information on the number of patients, on the treatments and care activities. More importantly, they have identified which treatments shouldn't be given to the patients.
- Although these centers were resistant at the beginning to collaborate in certain sensitive topics, now **they are more open to work together on research projects and to participate on new clinical trials.**

5. LESSONS LEARNED



- Some more traditional representatives of the centers didn't see the benefit of cooperation, they were not prepared to share their research and achievements. However, thanks to the multiple discussions, we have seen **changes in the way of working and the collaboration between the centers has increased significantly.**
- **Hevas was recognized as a neutral and trustful partner in this process.** The centers regularly express their gratitude to Hevas. According to them, it is more convenient that a patient organization takes a leadership role in this initiative and organizes the meetings. This helps to avoid political issue or competition between the centers.
- The fact that the National Centers of Expertise must be linked to an ERN in order to be able to get research funds from the EU in the future, is an **important incentive to participate in a national network.**
- This initiative could be scaled up to other diseases grouping in The Netherlands if **financial support is provided.** For now, VSOP has managed to get funds to develop the pilot Project Connect Extended but only for a limited number of Networks across the country.