Interview with PedCRIN consortium member Eric Vermeulen (VSOP, The Netherlands)

Interview to Eric Vermeulen

As part of our series of interviews with the PedCRIN Consortium members, we had the pleasure to speak with Eric Vermeulen to ask about the role of the Dutch Patient Organization for Rare and Genetic Diseases (VSOP) in the PedCRIN project.

VSOP co-leads PedCRIN Work Package 5 (Communication & Dissemination) along with Sant Joan de Déu Foundation (FSJD). The goals of WP5 are to communicate the project to children, parents and families, industry, regulatory authorities, policymakers, healthcare providers and all the relevant stakeholders and to ensure that children, young people, parents and families are included in the PedCRIN activities. Additionally, this WP aims at educating and empowering young patients and their families during the entire process of a clinical trial. VSOP is also dedicated to accomplish several tasks in WP2 Sustainability and WP4 Support to Multinational Trials. The main duties of VSOP in the PedCRIN project are “the involvement of patients/parents in the three pilot studies and to deliver communication about the project to other partners and stakeholders through the newsletter”.

When asked about how can PedCRIN contribute to the current European framework of paediatric research, Eric states that PedCRIN is well equipped to aid multicentre and multinational clinical research in paediatrics. “The organisation has a specifically trained staff
PedCRIN has received funding from the European Union’s Horizon 2020 programme under grant agreement number 731046.

dedicated to this particular job. It creates a network, but is more than a network. This is precisely the reason why PedCRIN is a reliable partner in aiding clinical research in multiple countries”.

Eric adds that PedCRIN can also help in involving patients and parents in clinical research. “Studies that request coordination or aid from PedCRIN can be stimulated to involve patients and parents during the process of writing the protocol and throughout the whole study”, he concludes.

Regarding the main outcomes expected from the project, Eric points out the following:

− Three pilot studies that have been successfully executed.
− Patients who have been consulted about them (by means of YPAGs and patient groups-interviews).
− Papers about patient involvement. One has already been published.
− Guidance about consultation methodology.

Eric considers that, so far, the development of the project is satisfactory. “PedCRIN has supported interesting studies and there is good cooperation among partners. We, as VSOP, have been able to consult patients about the supported studies and compare the findings with the outcomes of the YPAGs. These two groups — patient groups and YPAGs — are important venues for consultations about research, so that comparison is very interesting”.

On the other hand, he indicated that VSOP was not able to engage most ‘beneficiaries’ to contribute to the consultation of patient groups about the studies. He regrets this because, as he points out, “we could have learned from the patient perspective about medical and cultural aspects in different countries”.

Eric is of the opinion that the sustainability plan is very important for pediatric research in the future because, as he sustains, “PedCRIN is more than a network, it is an institution and therefore it can provide services and commitment of a trained staff, a feature that a network does not provide unless it is well organized”.

According to Eric, the pediatric research community, the patient associations and the YPAGs will benefit the most from a project like PedCRIN.

When asked what issues on academic paediatric clinical research need the biggest support, he replies that paediatric researchers need structural advice to estimate feasibility of research. “They also need advice and examples of patient involvement in research”, he highlights. “They have to learn that the involvement of patients and parents is possible and beneficial for clinical research and that this involvement should be accomplished in all phases of research”.