

Patient empowerment within the AnDDI-Rares network

Laurence Olivier-Faivre, Anne-Sophie Lapointe, Elisabeth Cudry, Françoise Nehaus

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The Reference Centers of the AnDDI-Rares network are encouraging the active participation of patients and carers in their health options, but also their participation in improving the general care and information in general.

In order to help them in choosing management options, different strategies are proposed:

- ★ Long clinics are proposed, from 45 minutes to 1 hour, in order to give information, but also to provide answers to the patient/family. Multidisciplinary clinics can be organized on demand, including psychologist and social care.
- ★ Functional evaluation of intellectual deficiency can be available at different moments of the life, in keeping with the project of life
- ★ A procedure for explaining the organigram and functioning of the reference center is available
- ★ Translators are available in site when needed
- ★ The letters of correspondence and results of tests are systematically transmitted to the patient/family as well as referring doctors
- ★ The center develop information material that are communicated to patients when appropriate, or propose validated documents of various sources specific to the disease, in their own language when they exist. This information is also available for non specialized centers
- ★ The center participate to the AnDDI-Rares blog, providing weekly information regarding rare diseases; and orientate patients/families on the Maladies Rares Info Services facility, a french help line that provide telephone and email personalized information and forums to be in contact with other patients, or rare connect for english speakers
- ★ Training can be offered on different manners, as it helps to empower patients and patients' representatives to disseminate best practice for rare diseases. Lectures, support groups for families and diverse activities can be proposed
- ★ Patients/families will be recontacted in case of progress in research, but a contact with the reference center on a 2-year basis at minimum is required for this purpose
- ★ There are procedures for obtaining patients consent

- ★ The patients/families can find within the reference center information regarding the possibility of obtaining their complete medical file, complaint and unanticipated outcomes
- ★ Results of research are transmitted to patients, individually or globally depending on the object of the research

The patients/families/patient organizations can also be part of the reference center life/planning:

- ★ The center evaluates the satisfaction of their patients and wishes to improve their services towards their patients. Their surveys are regularly improved with groups of patients. Other surveys can include the evaluation of adequacy and offers and demands.
- ★ The center receives volunteers from associations that have followed a specific formation in order to help patients in coping with some difficulties regarding the disease, and can give advice in organizing their follow-up
- ★ The center consults volunteers and associations for the construction and validation of documents of information, organizes lectures for the public with the involvement of patients or in co-organization with patient support groups, taking into account that patient experts have strong knowledge that is complementary to the medical knowledge, and can be transmitted in a more comprehensible manner
- ★ A joint work with the patient support group permits to reorientate patients in need in the reference center when needed, for example patients with no diagnosis when progress in genetic screening arose (next generation sequencing in particular)
- ★ Working groups have been launched regarding the deployment of therapeutic education programs
- ★ Patients can participate actively in research, as proposed in the GenIDA international project, a patient registry that notably aims at collecting data on the medical and therapeutic problems of patients with ID, with the intention of getting knowledge from the patients themselves.