

PROTOCOL

Attention to the students suffering from rare diseases by systems coordination

Servicio de Información y Orientación sobre ER

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FEDERACIÓN ESPAÑOLA DE ENFERMEDADES Raras

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Introduction:

Needs have to be known in their entirety to be addressed, are not isolated. They impact on all areas of the person. If they are tackled in an isolated way, the impact will be negative, preventing integral development and social inclusion. If they are addressed in full in a coordinated way the impact will favor both acceptance and personal development and social inclusion.

Coordination between systems is necessary to cover all the needs of the person in their environment, college, labor center, community, hospital, etc, these areas do not depend exclusively on a single system, to be addressed as a whole, it is necessary to establish coordination mechanisms that must be regulated by a normative framework for their effectiveness.

Conclusions:

We have detected in the process that the protocol will be effective if it is accompanied by the relevant regulations. Thus we have requested the Departments of Education and the Rare Diseases Advisory Council of the Departments of Health, include the following in the full inclusion decree: the educational compensation measures intended for these pupils "Periodic attention by healthcare staff in the educational center".

Objective:

Full School inclusion of students affected by rare diseases, who need regular health care at the school.

Results:

Protocol for the reception and care of children with rare or infrequent diseases in the schools of Extremadura.

http://enfermedades-raras.org/images/PROTOCOLO_ENFERMEDADES.pdf

Methodology:

Coordinated actions are established between FEDER and the Departments of Health and Education of the Junta de Extremadura with the purpose of facilitating the educational and socio-sanitary inclusion of the students with rare or infrequent disease in the educational centers of our region.

The protocol presents the following content:

1. Introduction.
2. The schooling of the child with suspicion or diagnosis of rare or infrequent diseases.
3. Plan of reception and attention in the educational center.
4. Links of interest.



Protocol awards:

- Awards FEDER 2015, to the Promotion and Defense of Human Rights.
- Extremadura Health Awards. Sanitaria 2000 has awarded the SANITARY ADMINISTRATION award to the Protocol. Mayo 2017.



Bibliography:

- Decreto 171/2009, de 24 de julio, por el que se crea el Consejo Asesor sobre Enfermedades Raras del Sistema Sanitario Público de Extremadura. DOE núm. 146, 30 de julio de 2009.
- Junta de Extremadura. Consejería de Sanidad y Dependencia. Plan Integral de Enfermedades Raras en Extremadura 2010-2014. Mérida: Consejería de Sanidad y Dependencia. Dirección General de Planificación, Ordenación y Coordinación; 2009.
- Protocolo DICE de Atención Primaria de Enfermedades Raras (DICE-APER) <http://dice-aper.semfyec.es/web/index.php>.
- Protocolo para la acogida y atención de los niños/as con enfermedades raras o poco frecuentes en los centros educativos de Extremadura. https://www.educarex.es/pub/cont/com/0004/documentos/PROTOCOLO_ENFERMEDADES.pdf