



---

**PROCEDURE FOR REVIEWS AND GUIDELINES FOR  
THE PROFESSIONAL ENCYCLOPAEDIA**

---

## OVERVIEW

### I- Objective

As a professional, you can send high-level articles to the Belgian Orphanet-team (orphanetbelgium@wiv-isp.be) in any language in order to diffuse them in the Orphanet website. This will enrich the Orphanet encyclopedia for professionals with Review articles or Clinical practice Guidelines on a rare disease or on a group of rare diseases published.

### II- Types of articles

The types of articles of interest for Orphanet are the following:

- **Reviews:** they provide a clear, up-to-date description of a rare disease (or a group of diseases). These reviews are intended to health professionals and scientists and generally published in peer-reviewed medical or scientific journals.
- **Clinical practice guidelines (CPGs):** systematically developed documents that aim at providing specific recommendations to standardise the process of diagnosis and treatment of clinical disorders for clinicians, patients and healthcare administrators. CPGs are published in peer-reviewed medical journals or in the form of guides or texts usually available on Internet (websites of medical societies, patient associations, networks, etc.).

## METHODOLOGY

### I. General procedure

There are five phases in the evaluation of external reviews and guidelines for the professional encyclopedia process:



### II. Description

#### 1. Identification and selection:

As a professional, you can send us articles. It should respect the following general inclusion criteria:

- The article is written in any language (so not necessary in English),
- The article deals with a rare disease, or a group of rare diseases,
- Reviews must be published in recognized (peer-reviewed) scientific/medical journals,
- CPGs must be published in recognized (peer-reviewed) scientific/medical journals, by recognized scientific societies/ health authorities or networks dedicated to rare diseases.

#### 2. Reviewing

The Orphanet Belgium team will then review the article, together with the coordinating Orphanet team. This includes the identification of the corresponding disease and the evaluation of the article following some preselected criteria.

### 3. Validation

Decision on publication of any evaluated document should be validated by the country coordinator and/or the coordinating Orphanet team (for articles in English and French).

### 4 & 5. Permission and Linking to Orphanet

Once the permission has been granted, the document can be linked to the disease pages, in the “detailed information” box:

...determines) and ocular anomalies (after treatment or replacement of a dislocated lens). Treatment is otherwise symptomatic. Prognosis depends on the degree of aortic involvement. With regular follow-up and adequate management, patients now have a life expectancy close to that of the general population. Over the last 30 years that life expectancy has increased by 30 years.

**Expert reviewer(s)**  
Pr Guillaume JONDEAU  
*Last update: March 2010*

Detailed information	
Emergency guidelines	<a href="#">English [↗]</a> (2007) <a href="#">Español [↗]</a> (2007) <a href="#">Français [↗]</a> (2007) <a href="#">Italiano [↗]</a> (2007) <a href="#">Portuques [↗]</a> (2007)
Review article	<a href="#">English [↗]</a> (2005,pdf) <a href="#">Français [↗]</a> (2005,pdf)
Clinical practice guidelines	<a href="#">Français [↗]</a> (2008,pdf)
Practical genetics	<a href="#">English [↗]</a> (2007,pdf)
Guidance for genetic testing	<a href="#">English [↗]</a> (2010,pdf)
Article for general public	<a href="#">Français [↗]</a> (2006,pdf)

Get Adobe

care by a qualified specialist and should not be used as a basis for diagnosis or treatment.