INVITATION TO PARTICIPATE IN THE DEVELOPMENT OF CLINICAL PRACTICE GUIDELINE ON RETINAL DYSTROPHIES

Dear Dir/Madam,

Following instructions of the Ministry of Health, Social Services and Equality and in close collaboration with the Federation of Patients' Associations for Retinitis Pigmentosa in Spain (FARPE) and the Spanish Society of Retina and Vitreous (SERV), we invite you to collaborate in the development of the Clinical Practice Guideline on retinal dystrophies.

The Ministry of Health, Social Services and Equality in its commitment to improve the health of the population and the quality and sustainability of the National Health System has commissioned to the Network of Health Technology Assessment of the National Health System, the development of a "Clinical Practice Guideline to improve the healthcare of people with retinal dystrophies". Within this network, the Evaluation Service of the Canary Islands Health Service (SESCS) will take responsibility for coordinating the design and implementation of the process of development of this guideline.

Bellow, there are the answers to some questions to explain how and why is important your participation in the development of the Clinical Practice Guideline.

What is a Clinical Practice Guideline?

It is an informative document to promote that health professionals can make more homogeneous diagnostic and therapeutic decisions according to the best scientific knowledge about effectiveness and safety.

What activities must be carried out to develop the Guideline?

To develop the "Clinical Practice Guideline on retinal dystrophies" two different but complementary activities will be sequentially carried out. The first one is a Review of the scientific literature (search, critical appraisal and synthesis of the available scientific knowledge) on the effectiveness and safety of diagnostic and therapeutic procedures to improve the healthcare and quality of life of patients. The second one will be to formulate recommendations for guide decisions making in a participatory manner between health professionals and patients.

Who will carry out these activities?

For the development of the guideline, participation of clinical experts in retinal dystrophies from different specialties, nurses and primary care physicians; but also patients and researchers with interest and experience in these diseases is required.

To carry out this tasks, the SESCS have established agreements with the Spanish Society of Retina and Vitreous (SERV) to share the responsibility and leadership of the development process.

At the same time, from the outset, FARPE has been involved to ensure that all process is properly guided by patients and their families in order to ensure that the contents of the Guideline respond to the needs and expectations of patients.

How can patients participate?

In most cases, the research questions arise from the ideas of researchers with little involvement of patients. For this reason, some potentially relevant issues for patients have not been investigated and remain unanswered.

We have now an opportunity for patients to help **guiding the contents of the "Guide retinal dystrophies" towards their own needs.** In addition, we intend to **identify those needs for patients that have not been sufficiently investigated** in order to transfer them to researchers interested in retinal dystrophies.

These two objectives pretend to be achieved through the **consultation** that you're welcome to respond. The consultation will consist of three rounds of questions. **In the first round we will ask you about your most important needs and concerns related to your retina problem.** In the next two rounds, we will try to sort, prioritize and reach consensus on all contributions made by the participants.

Yours sincerely

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