

# JRCD: a means to improve standards of care in rare cardiovascular diseases

## Dear Friends and Colleagues, Dear Readers,

I hope you will not mind me starting this Editorial with addressing, at first, Friends and Colleagues. This reflects the spirit of our new Journal. Our Friends and Colleagues have actively participated, over the last years, in our regional and national consultations on how to choose the best diagnostic and management path for patients with rare cardiovascular disorders. We believe that some examples of our prior work included in the present issue will attract your interest. We also hope that the format of these reports will find your approval. Each issue will also include regular papers and reviews on different aspects of rare cardiovascular diseases. What the last years have taught us is that it is necessary to record the “spoken words” into writing in order to create a formal platform for a wider flow of information and exchange of expertise. There is also no doubt that what is needed is a formal collaboration between centers *that professionally take care of “orphan” patients* to establish optimal and common diagnostic and management paths. What is also needed is planning and executing common registries that will lead to better understanding of the history of the disease. These are the main reasons for establishing the Journal.

Launching the *Journal of Rare Cardiovascular Diseases* fits in the current priorities of the European Commission (Priority 8 – Interregional Cooperation). Indeed, the Journal stems from a recent EU project, ‘Establishing a European Network for Orphan Cardiovascular Diseases’ (MRP0.08.02.00-12-424/10) and from establishing a regional Center for Rare Cardiovascular Diseases in Krakow (Poland) as part of this Project. The Journal is an independent educational initiative and it is registered under European laws. The *Journal of Rare Cardiovascular Diseases* is a peer-reviewed journal. We will aim for at least one reviewer from the country different than that of the manuscript submitting author. We are committed

to fertilizing the development of knowledge and its usefulness to YOU and YOUR patients. We will warmly welcome your participation. At a time of continuously increasing online scientific communication, and where success is based on establishing an efficient mutual communication, the *Journal of Rare Cardiovascular Diseases* joins the growing family of internet-based journals. We start with quarterly publication, and we aim to be indexed in the major medical data-bases with an impact factor. *The label of “orphan” should no longer be used.* Editing a journal is a major challenge, and we are very glad that a number of authorities have already accepted our invitation to the Editorial Board. We remain open, and will remain open to your suggestions to include those you know for their work with patients with rare cardiovascular disease. In conclusion, this Journal is about quality and about evolution of high-quality, common, standards in managing patients with rare cardiovascular disease. The idea to launch the *Journal of Rare Cardiovascular Diseases* crystallized at the first Satellite Meeting on Rare Cardiovascular Disease at the ESC in Paris in 2011. Not without a reason the first issue of the Journal coincides with the *International Conference on Rare Cardiovascular Diseases* in Krakow (October 18th–19th, 2012).

We hope you will enjoy reading the first issue of the *Journal of Rare Cardiovascular Diseases*. It includes work from several centers in countries such as Lithuania, France, Poland and the UK. I encourage you to read some original work on the shortcomings of the nitric oxide test in candidates for heart transplantation with severe pulmonary hypertension due to left ventricular systolic dysfunction, a review on the myocardial involvement in Fabry diseases, and case reports on practical aspects of managing patients with several rare cardiovascular disorders.

**Piotr Podolec**

Editor-in-Chief

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