



SOCIETE ROYALE BELGE DE RHUMATOLOGIE ASBL
KONINKLIJKE BELGISCHE VERENIGING VOOR REUMATOLOGIE VZW

+ 32 (0)2 372 36 43 | contact@r-euma.be | BE 0410.572.888 | Winston Churchilllaan 11/30, 1180 Ukkel
IBAN: BE94 3600 1056 4114 | RPR: Brussel/Bruxelles

Président - Voorzitter : Pr. Dr. V. BADOT

Vice-Président - Ondervoorzitter : Pr. Dr. P. VERSCHUEREN

Schatbewaarder - Trésorier : Dr. L. MERIC DE BELLEFON

Conseiller – Raadgever: Pr. Dr. P. DUREZ

Association Manager: Mrs. C. BAILLEUX

President-elect : Dr. J. LENAERTS

Algemeen Secretaris - Secrétaire Général : Dr. Y. PIETTE

Conseiller – Raadgever: Dr. P VOLDERS

Conseiller – Raadgever: Pr. Dr. D. ELEWAUT

Dear Colleagues,

In 2018 the Rare Diseases working group of KBVR-SRBR launched a call to create networks of centres involved in the care for the following Rare Diseases: systemic sclerosis, systemic lupus erythematosus, idiopathic inflammatory myopathies, vasculitis, juvenile arthritis and autoinflammatory disorders, metabolic and genetic bone disorders.

These networks reflect the reality of the expertise displayed by Belgian rheumatologists in the care of rheumatic disorders, in order to:

- Optimize the diagnosis and therapeutic decisions for patients with rare rheumatic diseases.
- Optimize the quality of care for those patients, by the creation of visible healthcare processes.
- Work on local guidelines about treatment, indications of new drugs, outcome measures, cost estimates.

This first call resulted in a listing of all centres (accessible via this link: www.r-euma.be), involved in the care of patients suffering from rare rheumatic diseases. We hereby demonstrate to all stakeholders our expertise in clinical care and our scientific activity dedicated to improve the outcome for these patient groups.

As regional, federal and European initiatives focusing on network development are rapidly evolving, we wish to boost this KBVR initiative and launch a second round for the Rare Diseases Centres from 2021 to 2023. This updated network will set the stage for the unfolding of the abovementioned initiatives and will foster Belgian initiatives.

The visibility of the network will be prioritised through the website and social media of KBVR/SRBR, to all rheumatologists and to the partners of the House of Rheumatology (ReumaNet, Clair, Belgian Health Professionals in Rheumatology).

Regarding the application process, centres may wish to apply for the first time, re-apply for the same level of expertise, or apply for another level of expertise.

When requesting a prolongation on the same level (Interested Centre (IC), Diagnosis and Treatment Competence Centre (DTCC) or Specific Care & Research Competence Centre (SCRCC)) a single motivation letter is requested. Please find enclosed the template for this letter. All Centres who are a Specific Care & Research Competence Center are asked to additionally submit a short report that contains all improvements for the rare disease(s) in the last three years. This can be scientific research, improvements of care for patients,

etc... These reports will be exposed during the Belgian Congress on Rheumatology in September 2021 in Brussels.

To apply for a higher level or in case of a first application: please fill in the full application form attached.

The selection of KBVR/SRBR Rare Rheumatic Diseases Centres is based on clinical and scientific criteria of excellence. The recognition is valid for a period of three years. Compliance of the candidate centres with the criteria is evaluated by the Rare Disease Working Group. If needed, an appeal procedure is in place with the support of the ERN ReCONNECT.

As of now, all prolongation and application forms can be sent to contact@r-euma.be by Saturday 31th of July 2021 at the latest.

Finally, interested colleagues are welcomed to join the Working Group.

Kind regards

Prof. Dr. Ellen de Langhe and Dr. Yves Piette
Presidents of the KBVR/SRBR Rare Diseases working group