

Survey response

<p>1. Brief description of the “Clinical Center” or “Services on undiagnosed rare diseases” (max 1000 characters). Please add a title to the short article/description you are going to send. Description should include information on: location contact person researchers staff existing program on undiagnosed rare diseases number of undiagnosed cases collected/year number of diagnosis obtained/year scientific advances/discoveries clinical research initiatives educational and collaborative opportunities</p>	<p>University Hospitals Leuven is a large tertiary referral center in Belgium. Among the first in Europe, University Hospitals Leuven are accredited by JCI (Joint Commission International) since 2010. Leuven University is ranked the most innovative university in Europe by Reuters. Very diverse clinical departments of the Leuven University Hospitals participate in 19 of the 23 European Reference Networks for rare diseases that were recently created. Leuven University Hospitals indeed have a longstanding tradition in the description and elucidation of new diseases or phenotypes. For the diagnostics in rare diseases and work-up of undiagnosed diseases, details of our Dept. of Human Genetics are relevant and can be found here: https://gbiomed.kuleuven.be/english/research/50000622/index.html Several dozens of undiagnosed patients are collected yearly.</p>
<p>2. Past (six months) and future/upcoming events related to undiagnosed rare disease. Please indicate date and venue.</p>	<p>http://www.rrd-foundation.org/en/course/inherited-disorders-metabolism-affecting-liver-management-and-outcome/94 institution-wide 'Rare Disease Council' yearly (upcoming october 29th)</p>
<p>3. Relevant scientific publications (selected and / or published by the center)</p>	<p>That's an impossible question. There are more than 100 clinical staff members and more than 200 researchers involved with all aspects of rare diseases in Leuven. When I perform a Pubmed search and restrict myself to the publications over the previous year, that I co-authored, I end up with 19 papers. Even those do not fit in the 1000 characters max imposed here.</p>
<p>4. Grants. a) grant award to announce funding for projects; b) Received grants from other organizations/institutions for undiagnosed rare diseases research.</p>	<p>Grants for Undiagnosed Diseases within the fields of mitochondrial diseases, CDG, immune deficiencies, genodermatoses, pulmonary hypertension, and many more ERN inclusion for 19 out of 23 ERNs as a clinical center</p>
<p>Contact</p>	<p>David Cassiman (david.cassiman@kuleuven.be)</p>