

FRENCH NATIONAL HEALTHCARE NETWORK FOR RARE ENDOCRINE DISEASES



The First Year of Activity to Monitor Patients with Rare Endocrine Diseases

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Introduction : Twenty-three national healthcare networks for rare diseases were identified in 2014 as part of the national plan on rare diseases and funded by the French Ministry of Health. The rare endocrine diseases national healthcare network FIRENDO (www.firendo.fr) includes 6 reference centers with complementary fields of expertise certified between 2005 and 2006, 30 centers of competence covering all French regions, 18 research and 37 diagnostic laboratories, 5 national learned societies and 14 patient advocacy groups. FIRENDO aims at promoting care and research in rare endocrine diseases and also provides epidemiological data on patients with rare endocrine diseases.

Methodology : Activity monitoring was instituted by FIRENDO through a network of 7 clinical research associates operating with a unified data collection procedure since January 2015. Data are collected using the CEMARA national database developed for rare diseases (<https://cemara.org>) for the expert reference centers and competence centers. In this first analysis, the data about out- and in-patients with rare endocrine diseases seen in the 6 reference centers has been analyzed. This analysis was focused on the 20 most frequent diagnosis in a total record of 16 000 patients registered in these 6 centers.

Main goals of FIRENDO network :



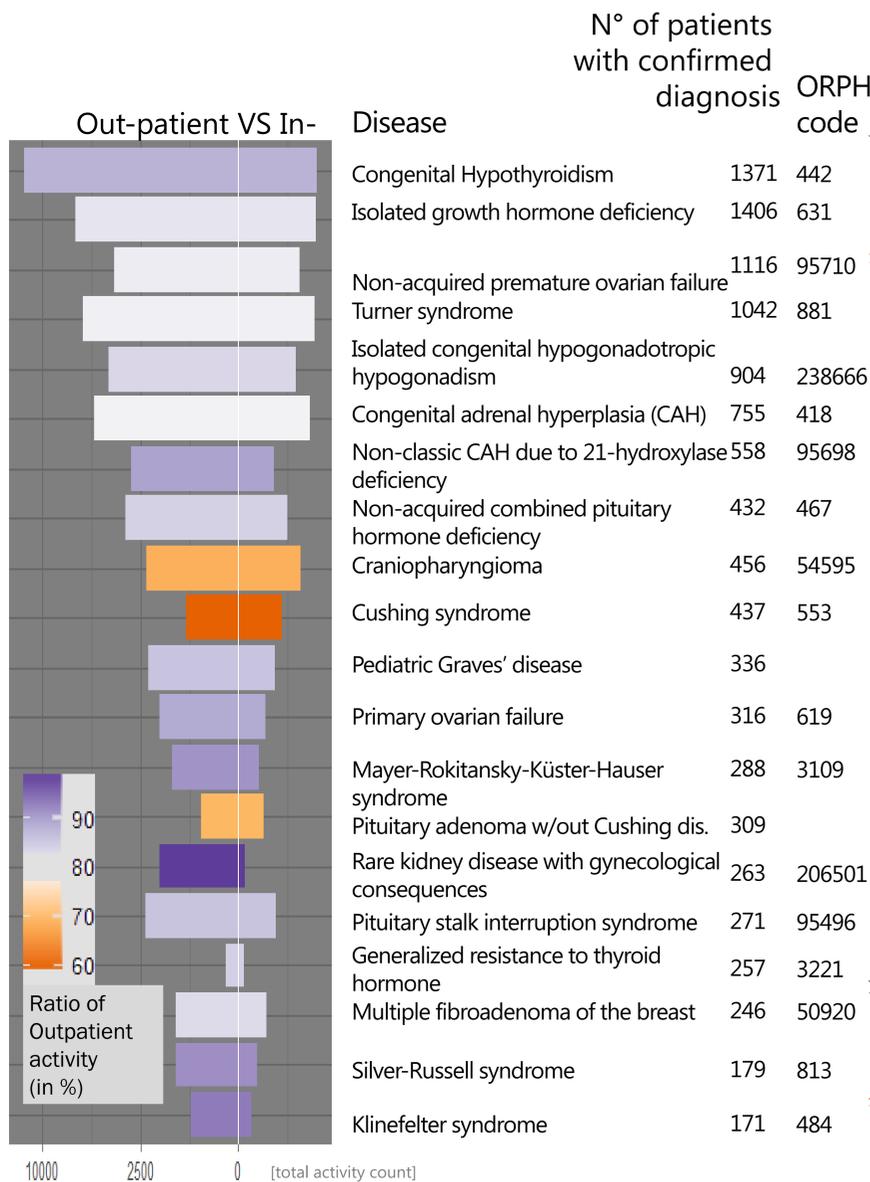
Improve patient management



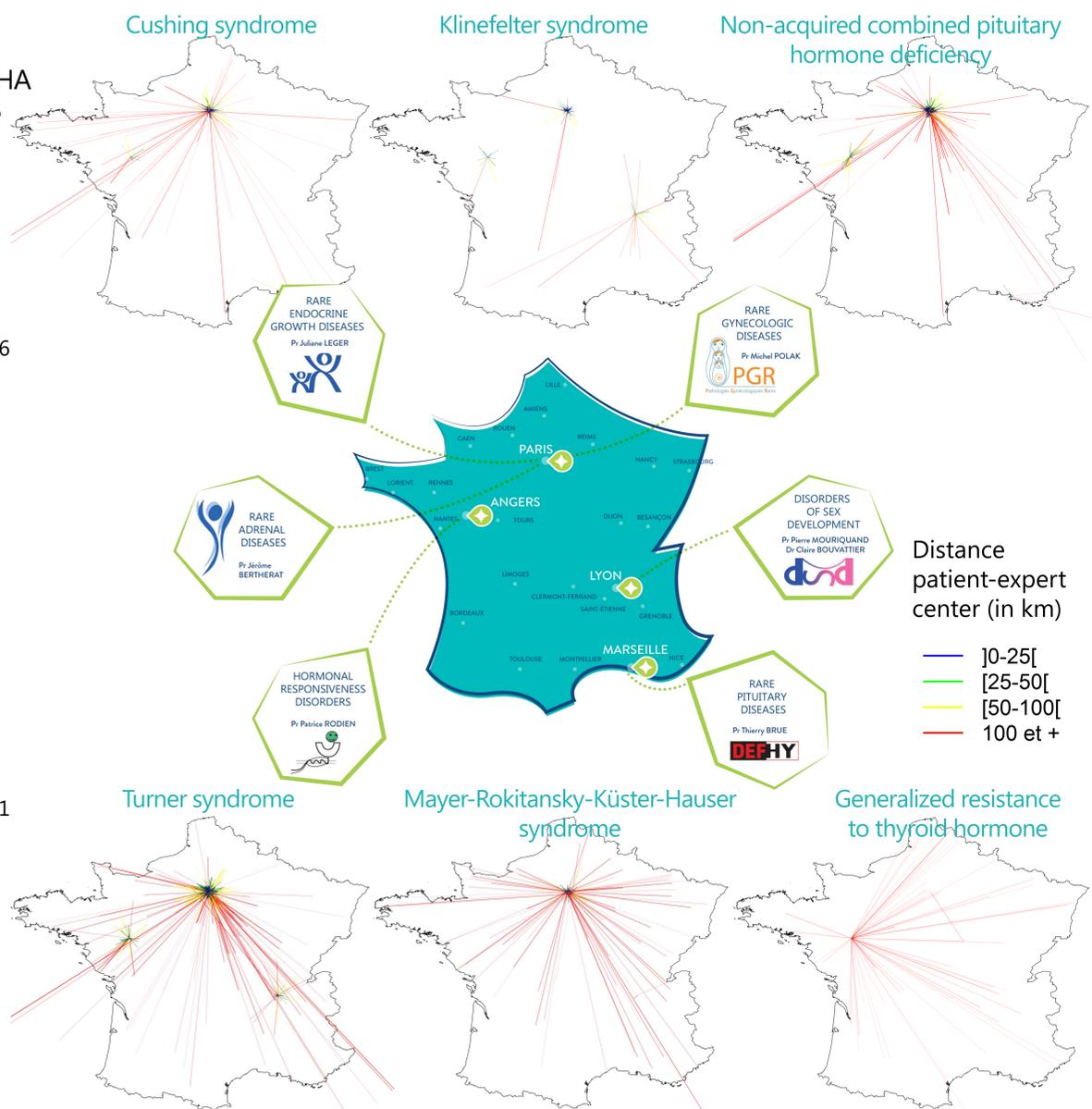
Inform about rare diseases



Pursue epidemiological surveillance



Outpatient VS inpatient activity breakdown and patient number for the top 20 most frequent rare endocrine diseases. CEMARA database provides the information about the disease prevalence and allows the follow-up of the activity type required for the care management. Some of the groups of phenomes can be further broken down to more specific diseases with ORPHA codes. Comparisons of out-/in-patient activity between regions or centers for the same disease can contribute to better informed public decisions.



Example of traveling distances to the expert centers for patients with one of the six frequent rare endocrine diseases. The minimal data set in CEMARA database allows the calculation of the average distances (shown here) or time required for the patient to reach the expert centers in France. Once again, this analysis can help a better retribution across the country of public funds dedicated to the care management of a particular rare disease. These infographics also pinpoint the portion of patients outside of continental France.

Conclusion : In 2 years since the inauguration of the national healthcare networks for rare diseases, FIRENDO has united nation-wide all the rare endocrine disease stakeholders. By placing the exploitation of the national database in the heart of its operations, FIRENDO should be able to build up a solid epidemiological tool to help monitoring rare endocrine diseases. This first draft allows a glimpse into the care management within 6 member reference centers. FIRENDO will provide more accurate data in years to come, therefore ensuring a more consistent healthcare and medical research scheme across all French regions.

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