French National Network dedicated to Rare Ovarian Malignant Tumors : epidemiologic data and comparison with a French regional cancer registry

E. Kalbacher^{1, 3}, N Chiannikulchai³, P. Pautier³, E. Pujade Lauraine³, A.S. Bats³, A. Floquet³, G Ferron³, C.Lefeuvre-Plesse³, C. Genestie³, M. Devouassoux-Shisheboran³, C. Pomel³, E. Leblanc³, M. Provansal³, C. Vacher-Lavenu³, I.Treilleux³, S.Croce³, F. Penault- Llorca³, E. Mery³, S. Henno³, G. Averous³, E. Guinaudeau³, F. Joly³, P. Meeus³, P.A Just³, N. Chopin³, F. Lecuru³, P. Morice³, F. Selle³, M. Provansal³, M.A. Le-frere-belda³, J.J. Terzibachian², T. DeLapparent², R.Ramanah¹, L. Courtois¹, L. Mansi¹, F. Bazan¹, M. Demarchi¹, L.Arnould³, M.P. Agros¹, A.S. Woronoff⁴, I. Ray-Coquard³

1- Department of Oncology, University Hospital of Besancon, France, 2- Gynecology Hospital Nord Franche- Comte, 3 -French National Network www.ovaire-rare.org, 4 –Doubs Cancer Registry

Background

Rare Ovarian Tumors (ROT) include several histological types. They represent more than 20% of all ovarian cancer. One of the major issue is to recognize these tumors and not to underestimate the fair value of incidence as no systematic review is proposed at the international level.

Methods

The French National Network dedicated to Rare Ovarian Malignant Tumors (ROMT) is organized with 3 national and 22 regional expert centers. We focus this study on the activities of the French Network ROMT from its beginning in 2011 to 2015, and this epidemiologic information in a French region, the Doubs, where a general registry is also performing registration. (Doubs represents 1% of the French population). We compared the capability of this network to be able to report strong data for incidence as all patients were systematically reviewed for histology. We analyzed data of the website of the French network and data of population-based cancer registry in Doubs: histology type, pathologic review.

Results

In the National Network from 2011 to 2015 there was a yearly progression of patients inclusion: from 553 to 1202, with an_increase of expert pathology review and patient discussion in dedicated multidisciplinary meetings from 166 cases in 2011 (25%) to 538 (45%) in 2015. In the Doubs region, from 2011 to 2015, 45 patients have been already recruited in the French National Network. In the Doubs registry cancer from 1995 to 2015, there were 211 patients with ROMT. Since 2011, number of patients with ROMT registered was quite similar between the two different approaches. All tumors of patients of the French network were reviewed by one of the onco-gynecological pathologist network referees, whereas it was uncommon for tumors of the population-based cancer registry. The distribution among histologies of ROMT was different: in the French Network website, sex cord-stromal tumor constituted 21% of malignant ROMT^{4p} (2nd larger group after borderline tumor). In the Doubs cancer registry, the mucinous tumors were the most frequent.

Conclusions

The French National Network provides medical advices and guidelines dedicated to rare ovarian tumor which are helpful for doctors, patients, families and health system. Network is critical for developing clinical research at the national and international level. Combination of the two approaches French network and cancer registry provides realistic incidence of rare tumors.