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## RARE DISEASES AMONG TOPICS ON EUROPEAN – CONGRESSES OF RADIOLOGY IN 2003 AND 2013

### Abstract

**Introduction and aim:** Rare diseases constitute an issue requiring special attention in radiology. The aim of the study was to determine a frequency of topics of rare diseases (RDs) on European Congresses of Radiology (ECR) of European Society of Radiology (ESR) in Vienna.

**Material and methods:** The study was based on two congresses of ESR in 2003 and 2013. The numbers of abstracts about RDs were counted as divided in a few sets: postgraduate educational programmes, scientific sessions and scientific exhibits. There was also a review of topics connected with RDs conducted.

**Results:** Percentages of abstracts about RDs were as follows: postgraduate educational programme 4% in 2003 and 6% in 2013, scientific sessions 3,3% in 2003 and 3,6% in 2013 and scientific exhibits 5% in 2003. There were also some samples of RDs-connected topics. These reports concerned various diagnostic methods.

**Conclusion:** RDs were present in many topics on ECR, but they were not of high frequency.

**Keywords:** Rare diseases, radiology, congresses as topic, education, history of medicine.

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## CHOROBY RZADKIE WŚRÓD TEMATÓW EUROPEJSKICH KONGRESÓW RADIOLOGII W 2003 I 2013 ROKU

### Streszczenie

**Wstęp i cele:** Choroby rzadkie stanowią zagadnienie wymagające szczególnej uwagi w radiologii. Celem badania była ocena częstości tematyki chorób rzadkich w pracach przedstawianych na Europejskich Kongresach Radiologii Europejskiego Towarzystwa Radiologii w Wiedniu.

**Materiał i metody:** Przedmiotem badania były dwa kongresy ESR w 2003 i 2013 roku. Liczby streszczeń na temat chorób rzadkich pogrupowano w kilka zbiorów: podyplomowe programy edukacyjne, sesje naukowe i wystawy naukowe. Dokonano również przeglądu prac pod kątem tematyki związanej z chorobami rzadkimi.

**Wyniki:** Odsetek streszczeń na temat chorób rzadkich był następujący: podyplomowe programy edukacyjne 4% w 2003 i 6% w 2013, sesje naukowe 3,3% w 2003 i 3,6% w 2013 oraz wystawy naukowe 5% w 2003. Stwierdzono również obecność prac o tematyce związanej z chorobami rzadkimi. Analizowane prace dotyczyły różnych metod diagnostycznych.

**Wnioski:** Tematyka chorób rzadkich była obecna w wystąpieniach na Europejskich Kongresach Radiologii lecz stanowiły one niewielki odsetek wszystkich prac.

**Słowa kluczowe:** Choroby rzadkie, radiologia, zjazdy, edukacja, historia medycyny.

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## 1. Introduction and aim

Rare diseases constitute an issue requiring special attention in medical practice, including medical diagnostics, especially diagnostic imaging. Because of the large number of rare diseases it is necessary to use additional sources of information to broaden the knowledge of doctors about little known diseases and abnormal clinical conditions [1]. Many forms of life-long learning may serve for this purpose, e.g. educational Internet portals with images and descriptions of lesions found in imaging studies, a databases of genetic diseases including semiotics of diseases and scientific conferences.

The aim of the study was to determine a frequency of topics of rare diseases on congresses of European Society of Radiology in Vienna, well-known scientific cyclic event with participants from many countries in the world present in the calendar of conferences for radiologists since 1967 [2].

## 2. Material and methods

The study was based on two ESR congresses: European Congresses of Radiology in 2003 and 2013. Their programs are accessible in the web portal of European Congress of Radiology <http://www.myesr.org/> and the periodical "European Radiology", including its electronic and printed forms, as 2013 one can be found in <http://www.myesr.org/>, <http://link.springer.com/journal/13244/4/1/suppl/page/1> and a printed volume "European Radiology" entitled "ECR 2003 / Final Programme / Supplement 1 to Volume 13 / February 2003". The numbers of abstracts about rare diseases were counted as divided in a few sets: postgraduate educational programmes, scientific sessions and scientific exhibit (absent in 2013). Only abstracts about rare diseases were counted, these that have names of rare diseases (or syndromes or disorders that are their components) in their titles or texts, but there was also a review of topics connected with rare diseases conducted, without quantitative analysis. Chairmans' introductions, discussions (including interactive case discussions) and other abstracts without text were excluded from the calculation. The definition prevalence of rare disease adopted for this study was under 1:2000 [3], [4].

## 3. Results

Percentages of abstracts about rare diseases were as follows: postgraduate educational programme 4% in 2003 and 6% in 2013, scientific sessions 3,3% in 2003 and 3,6% in 2013 and scientific exhibits 5% in 2003. Examples of rare diseases were: cystic fibrosis, tumors (e.g. neuro-endocrine, scrotal and brain tumors), male breast cancer, liver adenomatosis, echinococcosis, sarcoidosis and congenital anomalies. Some samples of rare diseases-connected topics were among others: hepatocellular carcinoma, congenital heart diseases, sensorineural hearing loss and congenital diaphragmatic hernia (Tab. 1-2). These works concerned various diagnostic methods.

Tab. 1. Sessions, lectures and reports on rare diseases and topics connected with them on European Congress of Radiology, 7-11 March 2003 in Vienna

Session A: Postgraduate Educational Programme ( <i>examples</i> )
1) Cáceres J., Vilar J.: <i>Thoracic calcifications</i> .
2) session: <i>Major and minor salivary glands</i> (moderator: Kainberger F.)
3) session: EURORAD: <i>Musculoskeletal cases presentation</i> (moderators: Bloem J. L., Kurdziel J.-C.)

4) Farina D.: <i>Aggressive lesions and benign tumors</i> (in the session “Nasal cavity and paranasal sinuses”)
Session B: Scientific Sessions ( <i>examples</i> )
1) Eichler K., Mack M.G., Zangos S., Straub R., Engelmann K., Vogl T.J.: <i>MR-guided LITT in patients with oligonodular hepatocellular carcinoma.</i>
2) Frei K.A., Kinkel K., Bonel H.M., Steiner R.A., Hylton N.M.: <i>Paget’s disease of the breast: Findings at MR imaging and histopathological correlation.</i>
3) Cyrylowski L., Gizewska M., Bilar A., Koziarska D., Nowacki P., Jozwiak I., Walczak M., Zdeb E., Romanowska H.: <i>Brain white matter changes in phenylketonuria: MRI, biochemical, neurological and psychological correlations.</i>
Session C: Scientific exhibits ( <i>examples</i> )
1) Tognini G., Ferrozzi F., Bini P., Giuliotti S., Patti A., Zompatori M.: <i>Verner-Morrison syndrome: CT and MR features.</i>
2) Mountanos I.G., Manolakakis S.I., Kotridis K., Karantanas A.H.: <i>Rare intraventricular brain tumors: CT and MR features.</i>

Tab. 2. Sessions, lectures and reports on rare diseases and topics connected with them on European Congress of Radiology, 7-11 March 2013 in Vienna [4]

Session A: Postgraduate Educational Programme ( <i>examples</i> )
1) Schima W.: <i>Solid tumours</i> (in the session ‘Malignant pancreatic tumours’).
2) Ertl-Wagner B.: <i>Neurocutaneous syndromes: more than neurofibromatosis.</i>
3) Rossi A.: <i>Patterns of white matter disease in children.</i>
4) Van Goethem J.: Venstermans C., De Belder F., van den Hauwe L., Parizel P. <i>Tumours of the spinal cord.</i>
Session B: Scientific Sessions ( <i>examples</i> )
1) Folio L.R., Derderian V.M., E.C. Jones, M.S. Merchant, Venkatesan A.M., Lotan E.: <i>Software validation of metastatic sarcoma lesion assessment using CT volumetric density tumour trajectory</i>
2) Liguori C., Di Giampietro I., Pitocco F., P. Cianciulli P., Beomonte Zobel B.: <i>β-thalassaemia as a new potential risk factor for left ventricular noncompaction (LVNC): a cardiac MRI evaluation.</i>
3) Yamashita K., Yoshiura T., Hiwatashi A., Togao O., Kikuchi K., Yoshimoto K., Honda H.: <i>Additive value of arterial spin labeling in differentiating primary central nervous system lymphoma from glioblastoma multiforme: an observer performance study.</i>
4) Ciet P., Gonzalez Graniel K., Stick S., Bruijne de M., Tiddens H.A.W.M., Van Straten M.: <i>Chest-CT protocol standardisation for multicentre trial in cystic fibrosis (CF) infants.</i>

#### 4. Discussion and conclusions

In the mentioned works problems of rare diseases were shown in various degrees of generality, according to the presented problem. In many reports studied issues were only mentioned by name, but in some in more detailed way, for example in the work “Neurocutaneous syndromes: more than neurofibromatosis” in session A of the European Congresses of Radiology in 2013 the attention was drawn not only to neurofibromatosis, the well-known by doctors entity, but developed putting information on other neuro-cutaneous syndromes as Sturge-Weber syndrome (Ertl-Wagner). Rare diseases were also mentioned as examples of diseases belonging to groups of diseases or disorders, e.g. neuroendocrine tumors as solid tumors in the session entitled “Malignant pancreatic tumours” in the session A of the European Con-

gress of Radiology in the year 2013 (Schima) [4]. They were also diseases that were subjects of studies of its imaging characteristics as Verner-Morrison syndrome (VIPoma).

Diagnosing of rare diseases is to conduct individualized treatment of patients. A manifestation of attempts to teach young doctors in that field resulting from the obligation of knowing the most common diseases and having basic knowledge on topics related to rare diseases is was an extraction of common and rare conditions that the doctor needs to know in a British specialization programs in radiology [4], [5], [6].

Rare diseases were present in many different topics on European Congresses of Radiology, but they were not of high frequency. At the same time, this study documents that, despite the huge number of rare diseases, the number of reports on this subject is meager and represents a small percentage of all the works discussed at the congress. From the estimates for many other conferences that figures that this congress is not isolated. The results of the analysis made by Skoczylas (2014) on exemplary medical conferences in 19<sup>th</sup>, 20<sup>th</sup> and 21<sup>th</sup> century, among others 67. *Versammlung deutscher Naturforscher und Ärzte in Lübeck* (1895, Lübeck), *Dreihundfünfzigste Tagung der Deutschen Gesellschaft für Pathologie* (1969, Mainz), *Fourth Asia and Oceania Congress of Nuclear Medicine* (1988, Taipei), reveals that most of the time of conferences is spent usually on discussing the most common clinical problems [4]. This issue is unappreciated, but as it is very difficult and often its subject not well-available, its presence on European Congresses of Radiology is worth emphasizing. This data only from years 2003 and 2013 is the results of a pilot study. It is planned to expand the analysis of the subsequent editions of the congress.

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