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Current efforts of Japanese public research groups on ADPKD

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In Japan, public services to support intractable diseases have been started, and ADPKD is also included. Our group study was supported in part by a Grant-in-Aid for Intractable Renal Diseases Research, Research on rare and intractable diseases, Health and Labour Sciences Research Grants from the Ministry of Health, Labour and Welfare of Japan. In this presentation, I will report on the actual state of ADPKD research in Japanese public research groups. There is a lack of evidence for ADPKD in Japan, and various information for medical professionals and patients is confusing. We confirmed the compliance rate of Japanese Clinical Practice Guideline for ADPKD from aggregation of clinical investigation personal form for the public services to support intractable diseases on ADPKD in Japan. We examined 3,768 newly registered cases from 2015 to 2016 and 2,085 renewed cases in 2017. In this study, 85.8% of the Japanese ADPKD patients had hypertension, and 92.3% were receiving antihypertensive treatment. We investigated the actual practice of cerebral aneurysm screening in Japan. We conducted an epidemiological study using a questionnaire survey to clarify the occurrence of cerebral aneurysms in ADPKD patients and the actual status of cerebral aneurysm screening in Japan. In this study, we obtained answers from 3,245 cases from 62 facilities nationwide in Japan. The mean age was 49.2 years. Male was There were 643 people (19.8%) with a family history of cerebral aneurysm. The median follow-up periods were 53 months. The incidence of cerebral aneurysms was 23.4/1000 person-years, and the incidence of rupture of cerebral aneurysms was 3.2/1000 person-years.

Keywords: ADPKD