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Session Topic : ADPKD

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## **Disease Notification to Children and Genetic Counselling**

**AKINARI SEKINE**

*Toranomon Hospital, Japan*

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I believe there is no "correct answer" regarding the timing and method of informing patients about the possibility of a hereditary disease. In actual clinical practice, I think the attending physicians from various departments take the lead in providing information about ADPKD genetics to patients as needed, but many doctors may find it difficult to inform children. It would be beneficial to consider in advance how to convey this information to children in their teenage years. It is important to inform patients that ADPKD is a hereditary disease, and that it may be shared within the family, not just by the patient. Ideally, all generations in the family—grandparents, parents, siblings, children, and grandchildren—should understand ADPKD and be able to communicate about the disease, regardless of whether they are affected. However, patients may feel anxious about passing their disease on to their children and may struggle to convey this information to them. To prevent children from feeling later that they were not informed about the potential hereditary nature of the disease, it is important for attending physicians to provide accurate information about the disease and genetics. Furthermore, genetic counseling plays a crucial role in providing such information. It is a space where individuals can discuss their experiences, beliefs, differences in values and thoughts between spouses or partners, and also consult about how to inform family members about the disease. Collaboration between the attending physicians from various departments and the genetics department is required. As a nephrologist specializing in ADPKD, and also as a clinical geneticist responsible for genetic counseling, I would like to talk about how I approach ADPKD patients, including the practical aspects.

**Keywords:** ADPKD, Disease Notification, Genetic Counseling, genetics, hereditary disease