



Leading European Nephrology

# NEWS

## European Renal Association – European Dialysis and Transplant Association

### European ADPKD Forum Position Statement puts the patients at the center!

**A study in the current issue of NDT [1] the European ADPKD Forum had published a position statement that offers a holistic approach to autosomal dominant polycystic kidney disease (ADPKD).**

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Autosomal dominant polycystic kidney disease (ADPKD) is the most common inherited kidney disease and the fourth most common cause of end-stage renal disease (ESRD). Many ADPKD patients eventually develop end-stage renal disease. In fact, ADPKD accounts for up to 10% of prevalent patients on renal replacement therapy (RRT).

In this position statement European ADPKD Forum postulates a holistic approach to the disease. It is not only about slowing disease progression, but especially about managing all aspects of ADPKD. Patients with this hereditary disease often suffer from hypertension and are at increased risk of cardiovascular and cerebrovascular events. Besides, pain is one of the leading symptoms of the disease. It often interferes with daily activities and causes physical and mental stress. Both have an effect on the quality of life of the patients and their social wellbeing – and can be associated with depression and fear. Therefore, ADPKD care programs should not only reflect the purely somatic aspects of the disease, but should recognize the potential psychological and social effects, too.

In summary, the authors postulate that a life-long, multidisciplinary, specialist and patient-centered care is needed. All patients should have access to a nephrologist with specialist ADPKD expertise as well as to other specialists, e.g. hepatologist, pain specialist, psychologist or clinical genetics specialist. Ideal would be the treatment in a specialized multidisciplinary ADPKD center. Another important pillar the authors emphasize is active patients' involvement and shared decision making. For this, better communication strategies and information resources would be needed to guide healthcare decision-making.

“This position statement takes a holistic view of ADPKD – and this is what makes it so valuable. It puts the patients at the center, not the disease”, explains Professor Denis Fouque, Lyon/France, NDT's editor-in-chief. “It is not about evaluating single treatment options and comparing outcomes.



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Instead, it gives a full picture of the disease and explains what patients really expect from ADPKD therapy.”

[1] European ADPKD Forum and Multispecialist Roundtable participants. European ADPKD Forum multidisciplinary position statement on autosomal dominant polycystic kidney disease care. NDT 2017. Link to the paper: [www.academic.oup.com/ndt/advance-article/doi/10.1093/ndt/gfx327/4772168](http://www.academic.oup.com/ndt/advance-article/doi/10.1093/ndt/gfx327/4772168)

### About ERA-EDTA

With more than 7,500 members, the ERA-EDTA ("European Renal Association – European Dialysis and Transplant Association") is one of the biggest nephrology associations worldwide and one of the most important and prestigious European Medical Associations. It supports basic and clinical research in the fields of clinical nephrology, dialysis, renal transplantation and related subjects. It also supports a number of studies as well as research groups and has founded a special "Fellowship Programme" for young investigators as well as grant programmes. In order to involve young nephrologists in all its activities ERA-EDTA has the "Young Nephrologists' Platform" (YNP), a very active committee whose board includes members who are 40 years old or younger. Besides, it has established various working groups to promote the collaboration of nephrologists with other medical disciplines (e.g. cardiology, immunology). Furthermore, a "European Renal Best Practice" (ERBP) advisory board was established by the ERA-EDTA to draw up and publish guidelines and position statements. Another important goal of the ERA-EDTA is education: several series of CME-courses as well as the annual congress offer an attractive scientific programme to cover the need of continuous medical education for doctors working in the fields of nephrology, dialysis and transplantation. The association's journals, NDT (Nephrology, Dialysis, Transplantation) and CKJ (Clinical Kidney Journal), are currently the leading nephrology journals in Europe; furthermore NDT-Educational is the online educational journal, open for free to all uses, of the Society as well as the very important and useful feature of NDT-Educational "Literature Review". The ERA-EDTA Registry is a large epidemiologic database comparing countries by assessing nephrology practice throughout Europe. ENP, the European Nephrology Portal, is the latest new initiative of ERA-EDTA: here all those interested in the activities of the Society can find everything that is done, all in one place! Finally, ERA-EDTA is a member of the European Kidney Health Alliance (EKHA), a consortium of patients, nurses, foundations all related to renal issues that actively interacts with the European Parliament. For more information please visit [www.era-edta.org](http://www.era-edta.org)