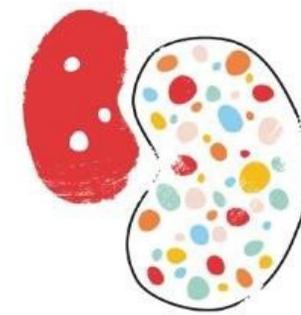


<https://www.adpedkd.org/>



ADPedKD

A small handbook for ADPedKD

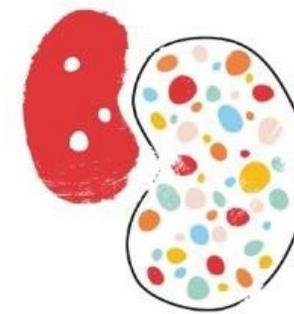
An international web-based database for longitudinal data registry of children with Autosomal Dominant Polycystic Kidney Disease (ADPKD)

Investigators:

D. Mekahli - S. De Rechter: UZ Leuven – KU Leuven, Belgium

M. Liebau - University Hospital of Cologne, Germany





ADPedKD

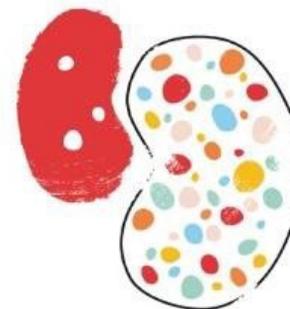
Initial steps necessary for participation:

1. Ethics approval: necessary in your country +/- your center?
2. If necessary: translation procedure of all documents (documents are available in Dutch, English, French, German, Italian, Polish, Portuguese, Romanian, Serbian, Spanish and Turkish via one of the investigators)
3. Registration on the website <https://www.adpedkd.org/>
after which you will receive an email containing your username and password

The screenshot shows the ADPedKD website interface. On the left, there is a navigation menu with the following items: [About ADPedKD](#), [Website Privacy Policy](#), [Links & Literature](#), [Registration form](#) (highlighted with a red box), and [Downloads](#). Below these are links for [ADPedKD global](#) and [Participating centers](#). The main content area features the ADPedKD logo, the text 'About ADPedKD', and a section titled 'About ADPKD and ADPedKD' which contains a paragraph of text about the disease. On the right side of the page, there is a login form with fields for 'Username' and a password field (indicated by asterisks), and a 'Login' button. An arrow from the third step of the list points to the 'Registration form' link in the navigation menu.



Registration form



ADPedKD

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[Links & Literature](#)

[Registration form](#)

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Supported by



Center information

Center name

Center address

Center phone

Center fax

Center WWW

Principal investigator

Principal Name

E-mail

Position

Study investigators

1. Name

1. E-mail

1. Position

2. Name

2. E-mail

2. Position

3. Name

3. E-mail

3. Position

4. Name

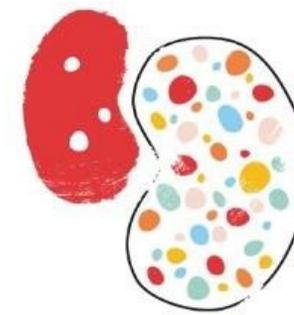
4. E-mail

4. Position

5. Name

5. E-mail

5. Position

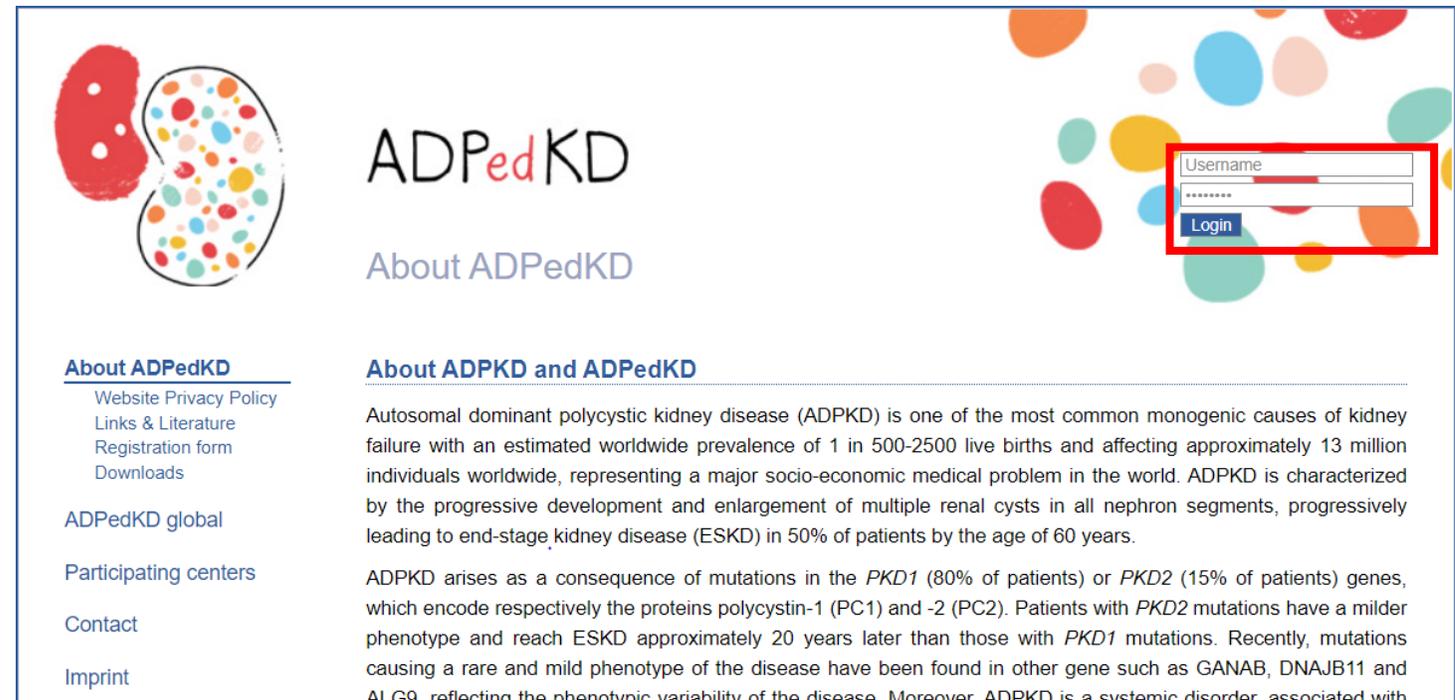


ADPedKD

Getting started with patient inclusion:

1. After receiving username and password and the approval of the corresponding ethics committee
2. You can enter patient data once your patient and/or a representative has received, understood and signed the patient information and informed consent form

Go to the website and log in :



About ADPedKD

- [Website Privacy Policy](#)
- [Links & Literature](#)
- [Registration form](#)
- [Downloads](#)

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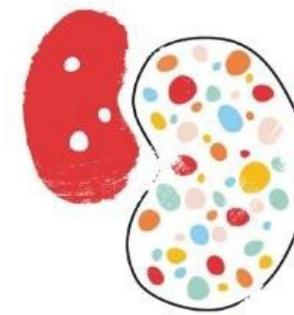
ADPedKD

About ADPedKD

About ADPKD and ADPedKD

Autosomal dominant polycystic kidney disease (ADPKD) is one of the most common monogenic causes of kidney failure with an estimated worldwide prevalence of 1 in 500-2500 live births and affecting approximately 13 million individuals worldwide, representing a major socio-economic medical problem in the world. ADPKD is characterized by the progressive development and enlargement of multiple renal cysts in all nephron segments, progressively leading to end-stage kidney disease (ESKD) in 50% of patients by the age of 60 years.

ADPKD arises as a consequence of mutations in the *PKD1* (80% of patients) or *PKD2* (15% of patients) genes, which encode respectively the proteins polycystin-1 (PC1) and -2 (PC2). Patients with *PKD2* mutations have a milder phenotype and reach ESKD approximately 20 years later than those with *PKD1* mutations. Recently, mutations causing a rare and mild phenotype of the disease have been found in other gene such as *GANAB*, *DNAJB11* and *AI G9* reflecting the phenotypic variability of the disease. Moreover ADPKD is a systemic disorder associated with



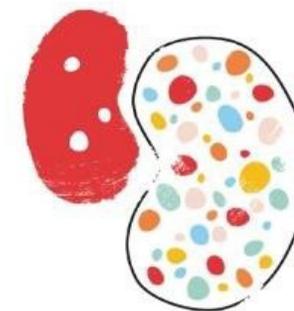
ADPedKD

Getting started with patient inclusion:

Go to „Patients registry“

The screenshot shows the ADPedKD Patients registry interface. On the left is a navigation menu with the following items: About ADPedKD, ADPedKD global, Participating centers, **Patients registry** (highlighted with a red box), User settings, Contact, Imprint, and Privacy Policy. The main content area features the ADPedKD logo, the text 'Patients registry', and a user login notification: 'You are logged in as vanmeerbeek' with a 'Logout' button. Below this is the center information: 'Center: Leuven, University Hospitals Leuven, Department of Pediatric Nephrology' and a button 'Add a new patient...'. A table titled 'Please click on a patient for more options...' lists patient records with columns for ID, gender and birth date, data completion status, and next visit date.

ID	Gender / Birth Date	Data Status	Next Visit
002-110	female * 05/2005	Basic data: Completed Visits: Completed	Next scheduled visit in 17 days
002-109	female * 06/2013	Basic data: Completed Visits: Completed	Next scheduled visit in 108 days
002-108	female * 09/2000	Basic data: Completed Visits: Completed	Next scheduled visit in 3 days
002-107	male * 02/2003	Basic data: Completed Visits: Completed	Next scheduled visit needed since 26 days
002-106	female * 12/2007	Basic data: Completed Visits: Completed	Next scheduled visit in 115 days
002-105	female * 09/2010	Basic data: Completed Visits: Completed	Next scheduled visit in 101 days



ADPedKD

Getting started with patient inclusion:

Then, click on „add a new patient“

ADPedKD

Patients registry

You are logged in as **vanmeerbeek**
Logout

[About ADPedKD](#)
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Center: Leuven, University Hospitals Leuven, Department of Pediatric Nephrology

Add a new patient...

Please click on a patient for more options...

002-110	female * 05/2005	Basic data: Completed Visits: Completed	Next scheduled visit in 17 days
002-109	female * 06/2013	Basic data: Completed Visits: Completed	Next scheduled visit in 108 days
002-108	female * 09/2000	Basic data: Completed Visits: Completed	Next scheduled visit in 3 days
002-107	male * 02/2003	Basic data: Completed Visits: Completed	Next scheduled visit needed since 26 days
002-106	female * 12/2007	Basic data: Completed Visits: Completed	Next scheduled visit in 115 days
002-105	female * 09/2010	Basic data: Completed Visits: Completed	Next scheduled visit in 101 days



Getting started with patient inclusion: Basic data

Then, you are directed to the “**Basic data**” section, which you need to fill in **only once**. This section covers general information on your patient, personal history, family history and the ADPKD diagnosis.

Please note:

- You can only continue after entering the Date of informed consent
- Questions marked with * are mandatory
- Patient ID will be generated automatically after saving, but please make sure you record this in your personal study documentation for future identification of this patient
- You can always enter data to the Basic data section later on as well



- About ADPedKD
- ADPedKD global
- Participating centers
- Patients registry**
- User settings
- Contact
- Imprint
- Privacy Policy

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Basic Data

Center: **Leuven, University Hospitals Leuven, Department of Pediatric Nephrology**

Please select...	Status
Personal information	-EMPTY-
Pre- and perinatal period	-EMPTY-
Initial diagnosis	-EMPTY-
Genetics	-EMPTY-
Family history	-EMPTY-

Patient-ID Will be generated after saving

IMPORTANT: Please don't forget to record the Patient-ID in your study documentation for future identification of this patient!

Personal information

Date of informed consent* (DD/MM/YYYY)
 Not required according to local regulations (confirmed by medical personnel including the patient)

Date of birth* (MM/YYYY)

Sex*

Dates

Date of diagnosis* (incl. prenatal)? (DD/MM/YYYY)¹ unknown

Week of gestational age (if prenatal): weeks

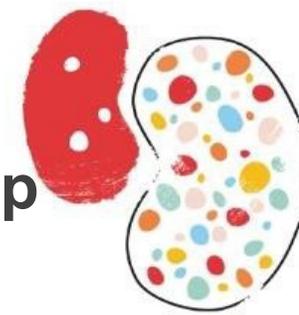
Initial visit at doctor* (incl. Obstetrics and Gynecology) (DD/MM/YYYY)¹ unknown

Important note: Fields marked with * are mandatory and will be READ ONLY after saving the initial visit. Please fill in with care.

¹ If exact data on day is not available, please enter 01 for the day.

[Save](#)

[next form »](#)
[Back to patients registry](#)



ADPedKD

Getting started with patient inclusion: Initial/ follow-up visits

In your Patients registry, you will be able to see whether a visit is needed. Please enter data at least once every year.

Click on **“Add initial visit”** in order to fill in the information of the first visit.

Click on **“Add next follow-up visit”** for every visit following the initial visit.

You can also click on **“Termination entry”** in case of death or loss of follow up or **“Transfer patient’s data to another ADPedKD center”**.

You also get an overview of all entered visits.

ADPedKD

Patients registry

Center: Leuven, University Hospitals Leuven, Department of Pediatric Nephrology

You are logged in as vanmeerbeek
Logout

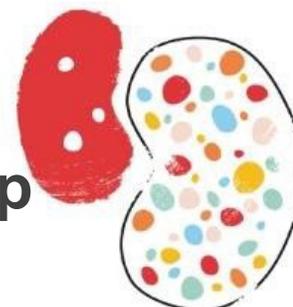
About ADPedKD
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Add a new patient...

Please click on a patient for more options...

002-110	female * 05/2005	Basic data: Completed Visits: Completed	Next scheduled visit in 17 days
<u>Basic data</u> » (completed)		Initial visit: 20/09/2019 » (completed)	Actions
Follow-up visits: 10/09/2020 » (completed) 01/07/2021 » (completed)		<u>Add next follow-up visit...</u> <u>Termination entry (death, loss of follow up)...</u> <u>Transfer patient's data to another ADPedKD center...</u>	
002-109	female * 06/2013	Basic data: Completed Visits: Completed	Next scheduled visit in 108 days
002-108	female * 09/2000	Basic data: Completed Visits: Completed	Next scheduled visit in 3 days

Getting started with patient inclusion: Initial/ follow-up visits



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Please note:

- Use "." as decimal marker
- Some values will be calculated / updated automatically after saving. This is written in the database.



ADPedKD

Patients registry



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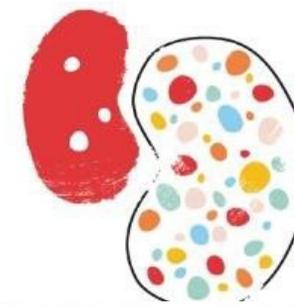


Center: [Leuven, University Hospitals Leuven, Department of Pediatric Nephrology](#)

[Add a new patient...](#)

Please click on a patient for more options...

002-110	female * 05/2005	Basic data: Completed Visits: Completed	Next scheduled visit in 17 days
<i>Visits</i>			
Basic data » (completed)	Initial visit: 20/09/2019 » (completed)		Actions
	Follow-up visits:		Add next follow-up visit...
	10/09/2020 » (completed)		Termination entry (death, loss of follow up)...
	01/07/2021 » (completed)		Transfer patient's data to another ADPedKD center...
002-109	female * 06/2013	Basic data: Completed Visits: Completed	Next scheduled visit in 108 days
002-108	female * 09/2000	Basic data: Completed Visits: Completed	Next scheduled visit in 3 days
002-107	male * 02/2003	Basic data: Completed Visits: Completed	Next scheduled visit needed since 26 days
002-106	female * 12/2007	Basic data: Completed Visits: Completed	Next scheduled visit in 115 days
002-105	female * 09/2010	Basic data: Completed Visits: Completed	Next scheduled visit in 101 days
002-104	male * 09/2008	Basic data: Completed Visits: Completed	Next scheduled visit in 115 days
002-103	female * 05/2006	Basic data: Completed Visits: Completed	Next scheduled visit in 87 days
002-102	male * 10/2008	Basic data: Completed Visits: Completed	Next scheduled visit in 115 days
002-101	male * 03/2018	Basic data: Completed Visits: Completed	Next scheduled visit in 108 days



ADPedKD

Questions when using ADPedKD?

Whenever you have any questions regarding ADPedKD, please do not hesitate to contact us by:

- Filling in the online Contact form
- Sending an email to

djalila.mekahli@uzleuven.be
kim.rowan@uzleuven.be
Lotte.vanmeerbeek@uzleuven.be

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[ADPedKD global](#)

[Participating centers](#)

[Contact](#)

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Contact form

Name

E-Mail

Message

Send

Send !

For any question please feel free to contact the study coordinators:

ADPedKD, Belgium



Djalila Mekahli



Angélique Dachy



Lotte Vanmeerbeek



Kim Rowan