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:
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PKD International

european society for paediatric nephrology

Leading European Nephrology

European Reference Network for rare or low prevalence complex diseases

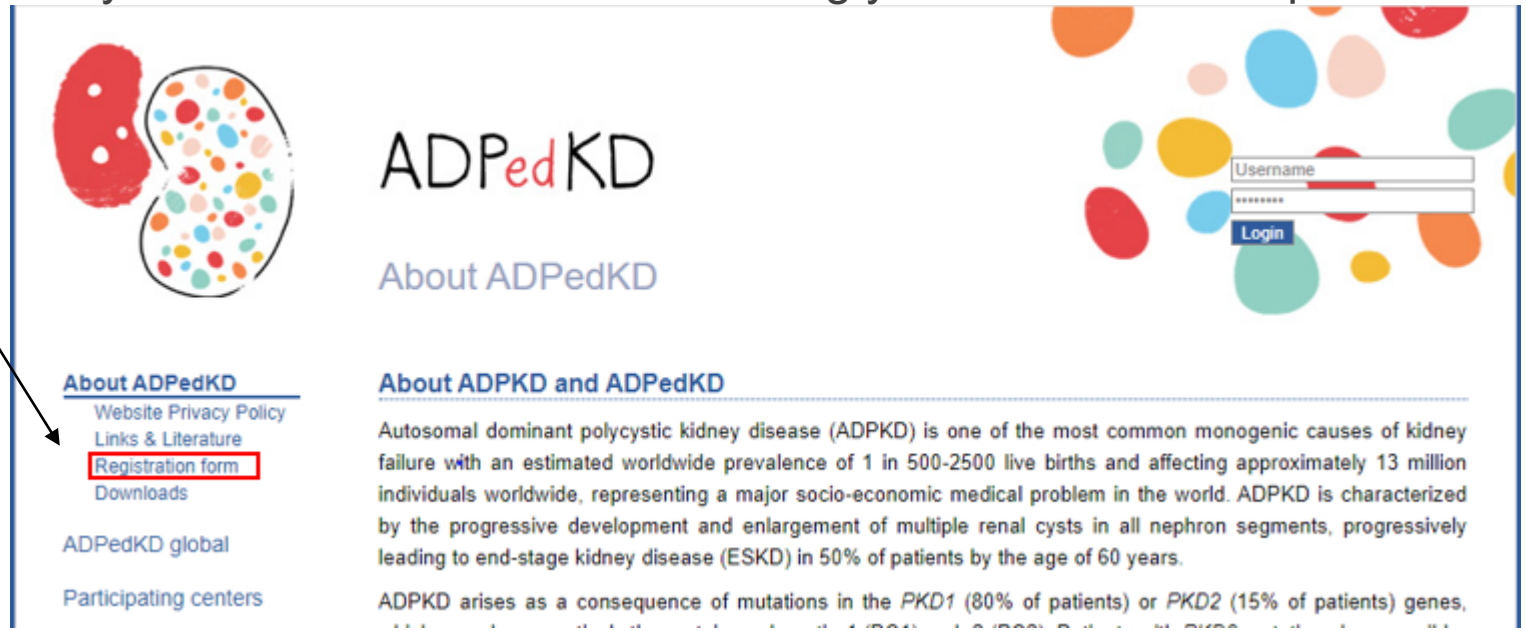
Network Kidney Diseases (ERKNet)

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



ADPedKD

Registration form

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Supported by

KU LEUVEN

UZ LEUVEN

GPN Gesellschaft für Pädiatrische Nephrologie

european society for paediatric nephrology

PKD International

ERA-EDTA Leading European Nephrology

ERKNet

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

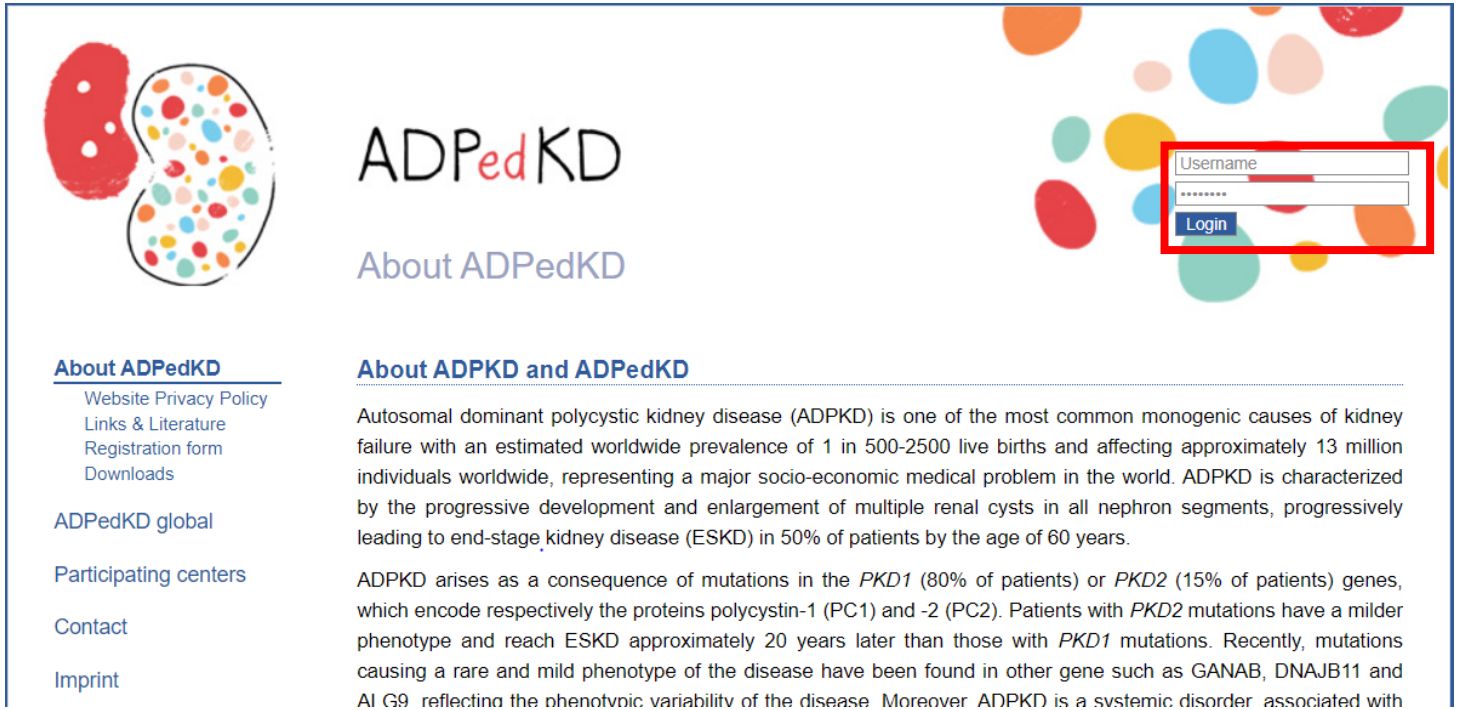
5. Name
5. E-mail
5. Position

Getting started with patient inclusion:

ADPedKD

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

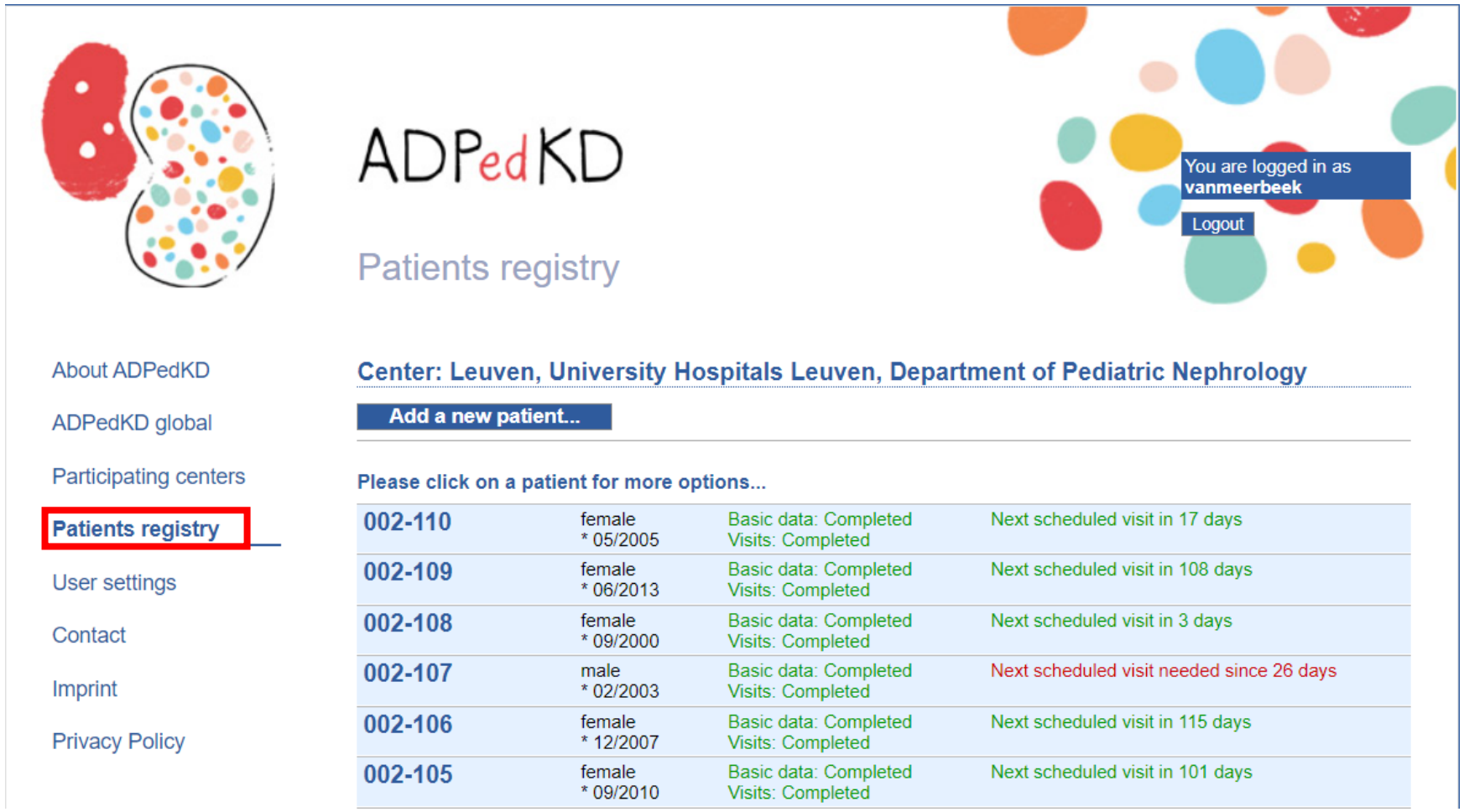
Go to the website and log in :



Getting started with patient inclusion:

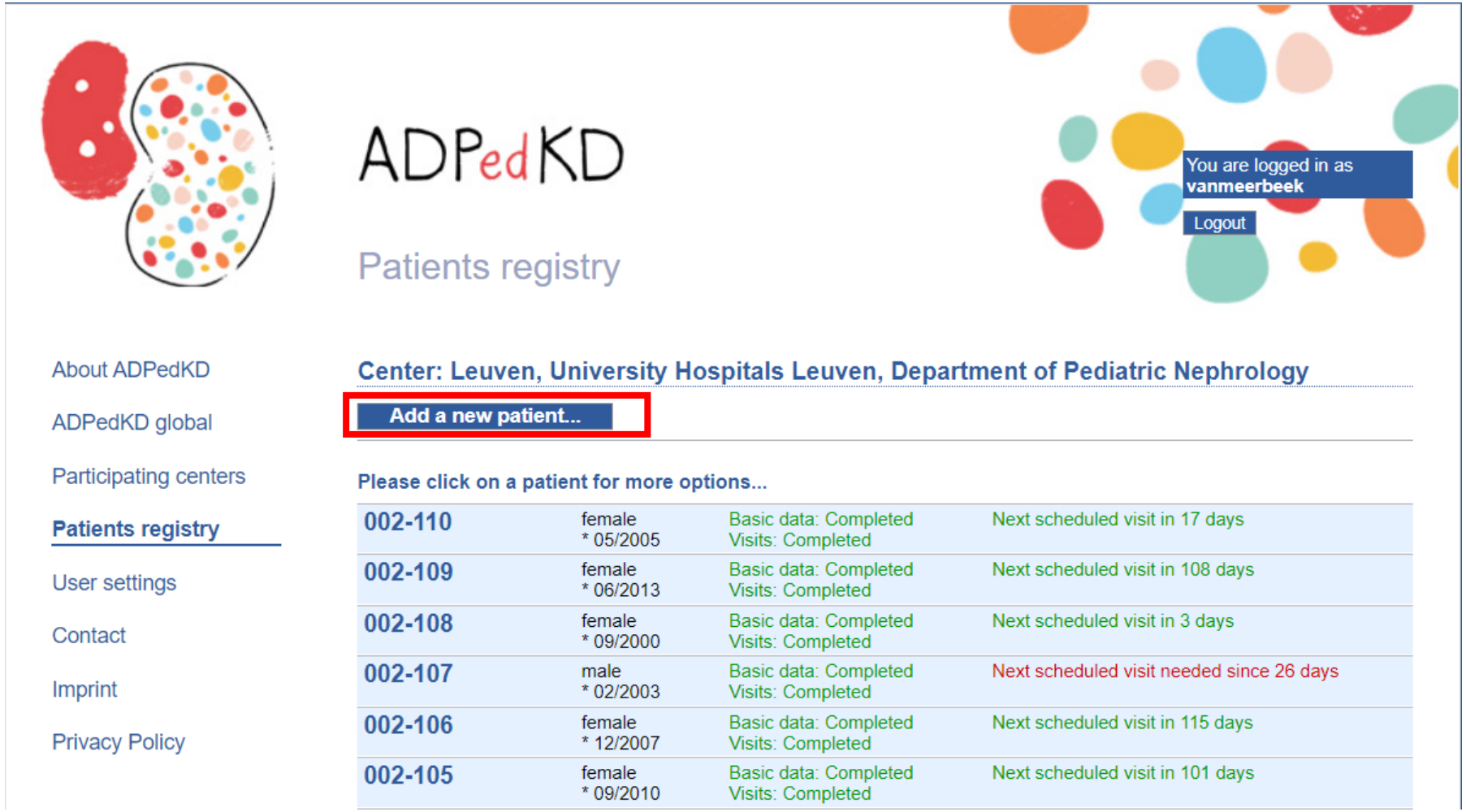
ADPedKD

Go to „Patients registry“



Getting started with patient inclusion:

Then, click on „add a new patient“

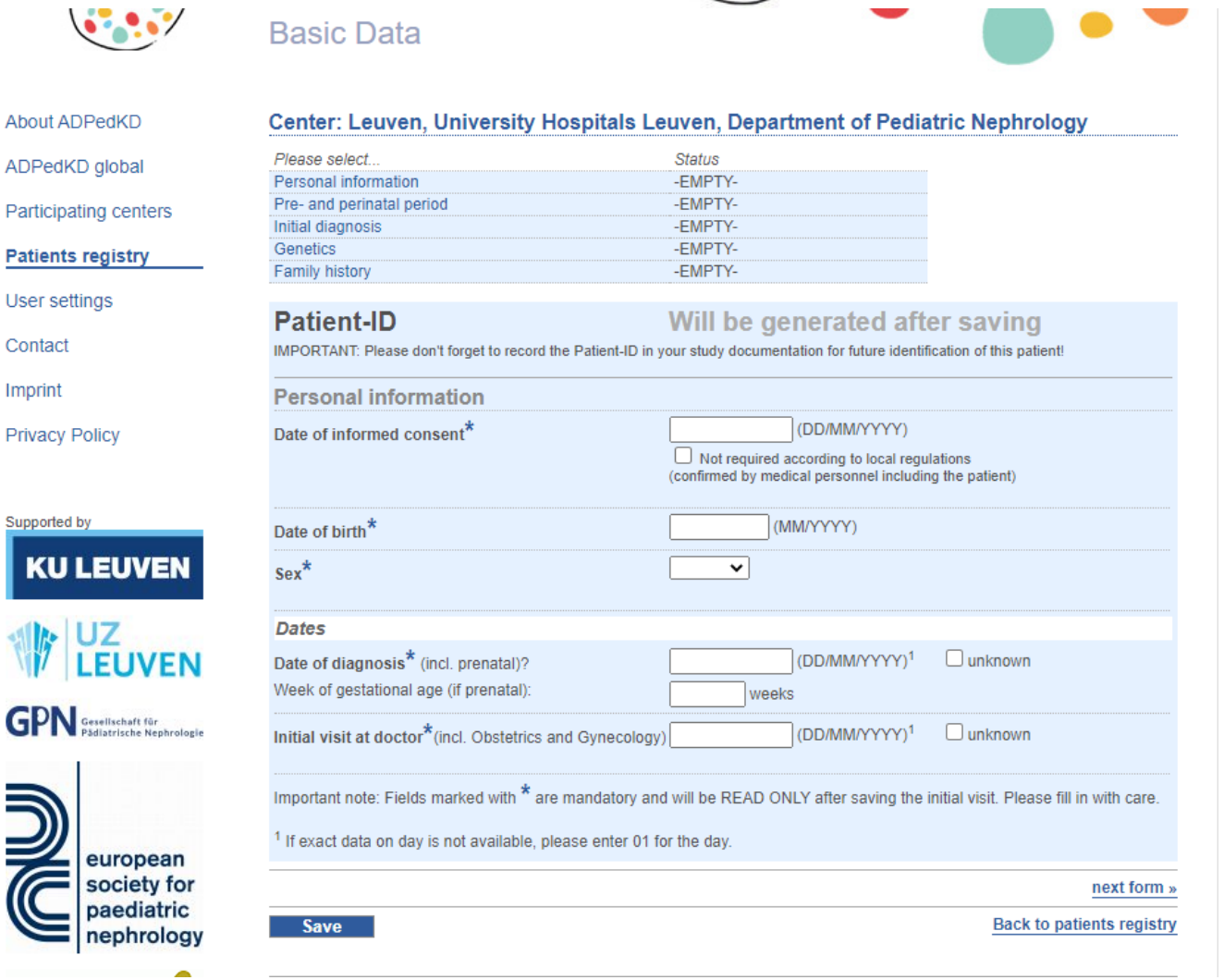


Getting started with patient inclusion: Basic data

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



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

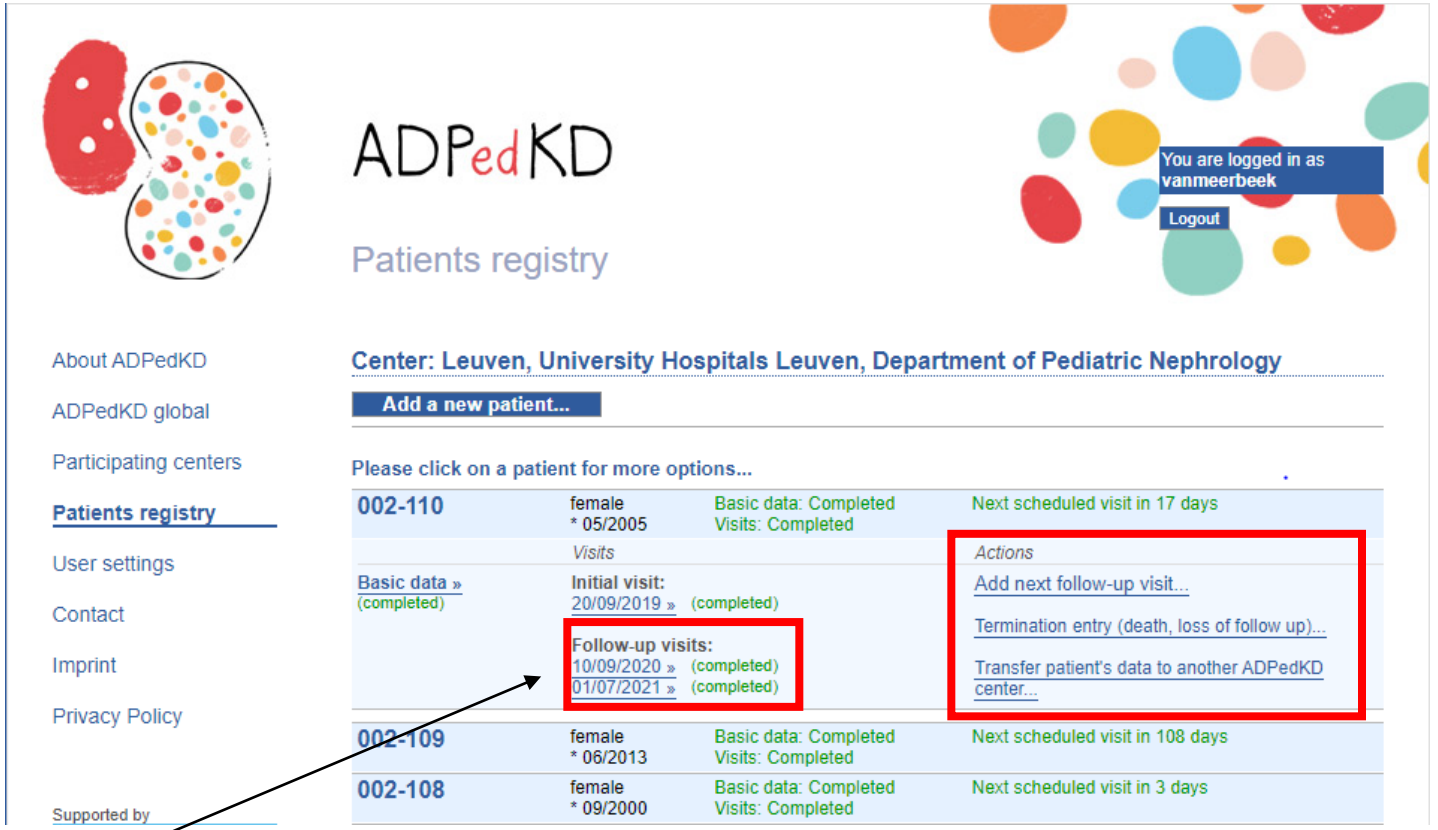
In your Patients registry, you will be able to see whether a visit is needed. Please enter data at least once every year.

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**”.

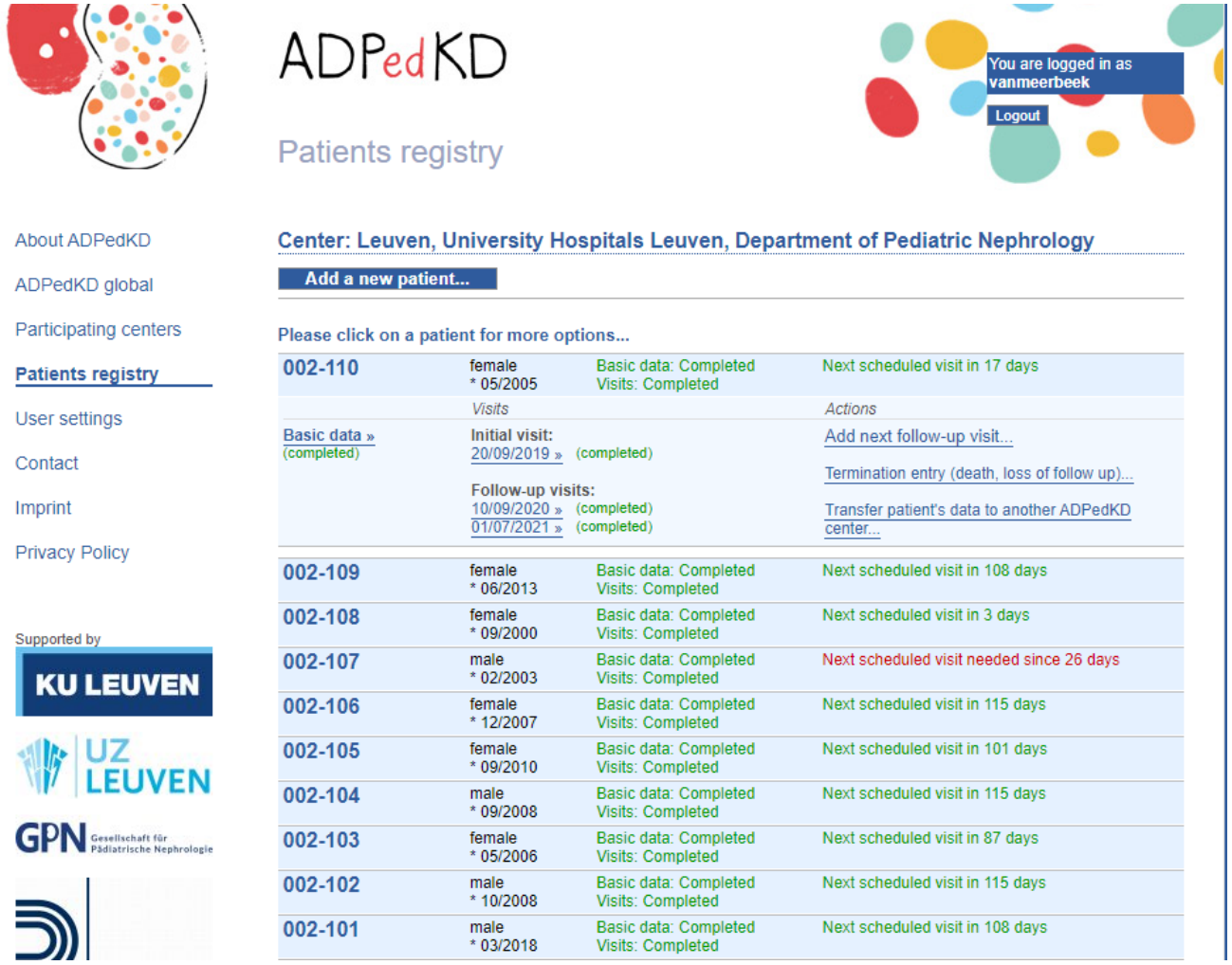
You also get an overview of all entered visits.



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

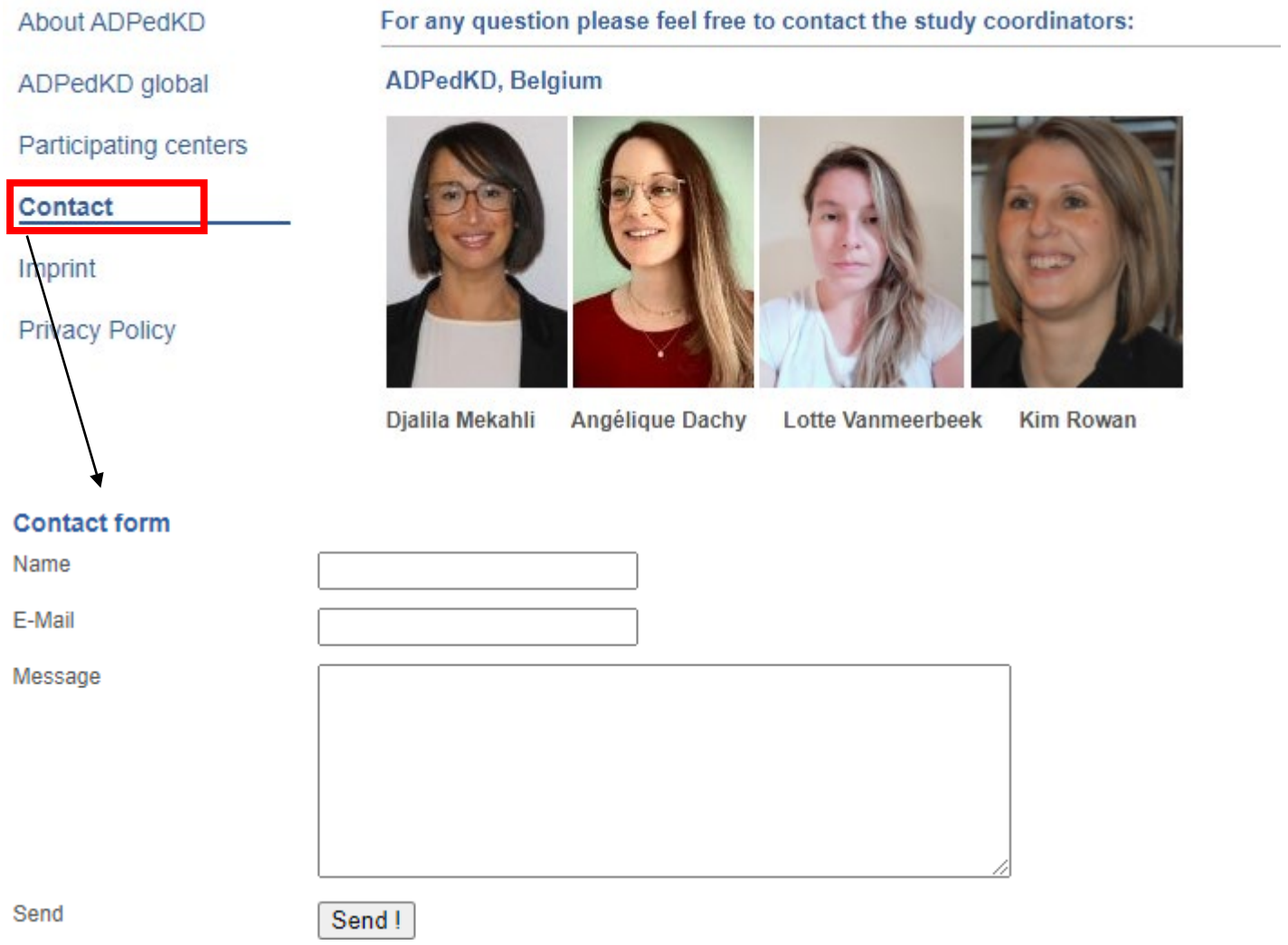
Please note:

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



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

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