



ERKReg

The European Rare Kidney Disease Registry



European
Reference
Networks

ERK-Reg User Guide

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ERKReg

The European Rare Kidney Disease Registry



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1. Welcome to the ERKNet Registry

ERKnet Registry, known as ERK-Reg, is a secure web-based application which has two major aims: (i) to identify contemporaneous cohorts of patients with rare renal disorders for clinical research across national borders., and (ii) to monitor treatment performance and patient outcomes in the participating centers. Moreover, the registry allows to integrate detailed disease-specific registries as extensions to the core database.

The core registry made for ERKNet

The recent implementation of European Reference Networks for Rare Diseases (ERNs) is an unprecedented move to improve the care of patients suffering from rare health disorders by transnational collaboration. ERKNet, the ERN for Rare Kidney Diseases, oversees more than 43,000 patients in 38 specialist centers. The Network members are committed to collaborating closely in order to improve the health outcomes of their pediatric and adult patients with rare kidney disorders. Core objectives of the collaboration will be the implementation of clinical practice guidelines and the definition and prospective monitoring of core indicators of guideline conforming management, treatment quality and patient health outcomes.

Clinical registries are indispensable instruments to provide demographic, genotype-phenotype and natural history information. The ERKNet centers are currently active in more than 60 mostly disease specific registries, most of which are limited to regional or national patient coverage. While the existing registries are collecting important information, none of them is currently used in all ERKNet centers. This paradigm of a Web based registry with an immediate benefit to user centers can serve as a blueprint for a Network wide registry in ERKNet that, interconnected with and complementary to the existing rare kidney disease registries, will have a clear **patient-oriented focus on healthcare quality improvement**.



2. Getting Started

2.1. Access to ERK-Reg

Access to the ERKNet Registry (ERK-Reg) is strictly regulated to protect the data privacy rights of the patients. Only authenticated users can request access to use the ERK-Reg. The username and password are strictly personal and may be requested to be provided to the ERKNet Help Desk team member in charge of your country of origin. Accounts for co-workers can be created at the direct request of the Center Coordinator. ERKNet has member Healthcare Provider **centres** (HCP) and it is envisaged that the users of ERK-Reg are Health Professionals (HP) within these Healthcare Provider **centres** (HCPs).

2.2. Request Access to ERK-Reg

This document explains how to request access to **ERK-Reg**. To be able to start, the first requirement for the user is to request a login. On this purpose, please send an e-mail request to the help desk member responsible for your country.

Germany, UK : Tanja Wlodkowski (tanja.wlodkowski@med.uni-heidelberg.de)

Belgium, The Netherlands: Ilse Rood (Ilse.Rood@radboudumc.nl)

Italy: Giulia Bassanese (giulia.bassanese@med.uni-heidelberg.de)

Poland, Czech Republic, Lithuania, Schweden: Magda Duklas (mduklas@gumed.edu.pl)

Spain, France: Victor Perez Beltan (victorpbeltan@gmail.com)

All the other Countries (affiliated partners):

Tanja Wlodkowski (tanja.wlodkowski@med.uni-heidelberg.de)

Giulia Bassanese (giulia.bassanese@med.uni-heidelberg.de)



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The European Rare Kidney Disease Registry



2.3 Logging In

The application can be accessed through web-browsers. For best experience, make sure you are using a supported browser. ERK-Reg is supported to its full potentials on **Google Chrome** and **Mozilla Firefox** preferably latest version.

You can access the registry by the ERKNet page webpage by clicking <https://www.erknet.org>

When you have an ERK-Reg login account (which can be used to access multiple ERKNet systems), **enter username** and **the password provided** by the help desk member and click on the button "Login" .



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ERKNet

The European Rare Kidney Disease Reference Network



Home Our Experts ▾ Disease Information Virtual Consultation Guidelines & Pathways ▾ Registries ▾ Education & Training ▾ Research ▾ The ERNs

ERKNet is the **European Reference Network for Rare Kidney Diseases**, a consortium of 38 expert pediatric and adult nephrology centers in 12 European countries providing healthcare to more than 40,000 patients with rare disorders of the kidneys.

The ERKNet partners offer **top quality multidisciplinary healthcare** for a wide range of rare kidney disorders. They uniformly apply clinical guidelines and pathways according to latest medical knowledge and strictly monitor the quality and outcomes of therapy across the Network.

ERKNet offers **virtual consultation services** to physicians throughout Europe who need advice for challenging cases with a rare kidney disease.

ERKNet is dedicated to improve **knowledge about rare kidney diseases** among patients and healthcare professionals. We disseminate disease information via this website and by multiple **education and training** activities.

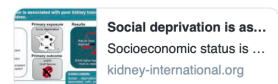
ERKNet actively supports **clinical research** to improve diagnosis and risk prediction and advance the development of new therapies for patients with rare kidney disorders.

In pursuing these tasks, ERKNet closely collaborates with the corresponding expert workgroups of the European nephrology societies: The **Workgroup for Inherited Kidney Diseases (WGIKD)** of the European Renal Association / European Dialysis and Transplant Association (ERA-EDTA), and the **Working Groups of the European**



Tweets by @EuRefNetwork

ERKNet
@EuRefNetwork
Social deprivation is associated with poor #kidney #transplantation outcome in children
[kidney-international.org/article/S0085-4142\(19\)30085-1](https://www.kidney-international.org/article/S0085-4142(19)30085-1)



Jun 2, 2019

ERKNet
@EuRefNetwork
#Eculizumab deposits in #renal arterioles was observed since day 1 up to more than 5 months after therapy discontinuation in patients with #TMA kidney-
[kidney-international.org/article/S0085-4142\(19\)30085-1](https://www.kidney-international.org/article/S0085-4142(19)30085-1)

Figure 1: ERKNet home page

Once you have logged in, you can access the registry by clicking on "Registry" and choose "ERK-Reg" as showed in Figure 2.



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ERKReg
Associated Registries

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Username
Password
Login

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ERKNet
@EuRefNetwork
Social deprivation is associated with poor #kidney #transplantation outcome in children kidney-international.org/article/S0085-...

Social deprivation is as...
Socioeconomic status is ...
kidney-international.org

Jun 2, 2019

ERKNet
@EuRefNetwork
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era edta
WGIKD
working group

European society for paediatric nephrology

Figure 2: ERKNet home page

2.4. ERK-Reg Support Desk

In case you have any technical difficulty logging into the ERK-Reg or using any of its services, please contact the support team via email tanja.wlodkowski@med.uni-heidelberg.de. Please send your feedback, suggestions, or complaints to the support team.



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3. Accessing ERK-Reg Applications

Successfully logging in to the Registry, it will direct the user to the **Registry start Page** as displayed below:

You are logged in as **admin_bassanese**

[Logout](#)

- [Registry start page](#)
- [Data entry](#)
- [Export data](#)
- [Export dRTA data](#)
- [Export Alport data](#)
- [KPI Monitoring](#)
- [Enrolment by center](#)
- [Downloads](#)
- [Administration Area](#)
- [EUPID-TEST](#)

[ERKNet Home Page](#)

The ERKNet Consortium follows all consenting patients with rare kidney diseases prospectively in a central registry. The ERKNet registry serves two main purposes:

- To inform how many patients with individual rare renal diseases are treated across the Network and where they are located. Clinical, genetic and histopathological diagnoses are recorded as appropriate. This will allow to identify and contact patients with a given disorder rapidly whenever novel therapeutic opportunities arise.
- To comply with the Network's mission to provide excellent treatment quality to all patients. Selected disease- or treatment-specific quality and performance indicators are monitored at the patient level. This will permit the participating European Reference Centers to review their diagnostic and therapeutic performance as well as patient outcomes relative to those achieved in the Network as a whole.

Current Number of Patients enrolled in the ERKNet-Registry

	All ERKNet centers					
	pediatric		adult		total	
	total	active	total	active	total	active
Glomerulopathies	308	308	203	189	511	497
Tubulopathies	126	114	11	9	137	123
Metabolic nephropathies	62	60	15	8	77	68
Thrombotic microangiopathies	53	46	9	9	62	55
CAKUT and ciliopathies	202	193	6	6	208	199
AD structural disorders	126	122	63	63	189	185
TOTAL	877	843	307	284	1184	1127
Pediatric CKD and dialysis	707	706				
Pediatric transplantation	162	162				

Figure 3: Registry start page

3.1. Accessing the ERK-Reg

Successfully logging in to the ERK-Reg, it will direct the user to the **Main Dashboard Page** as displayed below:



ERKReg

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ERKReg

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You are logged in as
admin_bassanese

Logout

Registry start page

Data entry

Export data

Export dRTA data

Export Alport data

KPI Monitoring

Enrolment by center

Downloads

Administration Area

EUPID-TEST

ERKNet Home Page

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AD structural disorders	126	122	63	63	189	185
TOTAL	877	843	307	284	1184	1127
Pediatric CKD and dialysis	707	706				
Pediatric transplantation	162	162				

Figure 4: ERK-Reg main Dashboard page

1. Clicking here will always direct the Registry start page from anywhere in the system.
2. „Data entry“ will allow the user to access the page where to enter patients data.
3. Allow the user to export via Excel spreadsheet all the data relating to patients in his Centre entered in the Registry.
4. Enable the user to export via Excel spreadsheet all the data relating to patients in his Centre entered in the dRTA sub-registry.
5. Allow the user to export via Excel spreadsheet all the data relating to patients in his Centre entered in the Italian Alport sub-registry (only for Italian ERKNet users).
6. By clicking here is available a statistic table with the updated number of patients enrolled in the ERKNet-Registry.



7. In „downloads“ is available the informed consents and all documentation about ERK-Reg i PDF.

4. Data entry

The screenshot shows the ERKReg web application interface. On the left is a sidebar menu with options like 'Registry start page', 'Data entry', 'Admin: Select Center', 'Export data', 'Export dRTA data', 'Export Alport data', 'KPI Monitoring', 'Enrolment by center', 'Downloads', 'Administration Area', 'EUPID-TEST', and 'ERKNet Home Page'. The main content area is titled 'Center: Wiesenbach, Test Center external'. It features a 'Patient filter' section with dropdown menus for 'order by: Patient ID [descending]', '[Both units]', '[All visits]', '[All CKD stages]', '[All treatments]', '[All registries]', '[All disease groups / diagnoses]', and '[Family filter]'. Below this is a table of patients with columns for patient ID, sex, date of birth, disease group, CKD stage, next visit due date, and a delete icon (red cross). Numbered callouts point to specific elements: 1 points to the 'Add a new patient...' button; 2 points to the delete icon; 3 points to the patient ID; 4 points to the sex and date of birth; 5 points to the disease group; 6 points to the CKD stage; and 7 points to the next visit due date.

Patient ID	Sex	Date of Birth	Disease Group	CKD Stage	Next visit due	Delete
500-0006	P	M-01/2010	Metabolic nephropathy	CKD3	Next visit due: 05/05/2020	✖
500-0005	P	M-01/2008	Glomerulopathy (Alport-Patient)	CKD5	Next visit due: 01/05/2020	✖
500-0004	P	M-01/2010	Glomerulopathy	CKD4	Next visit due: 01/04/2020	✖
500-0002	A	F-01/1975	Glomerulopathy (Alport-Patient)	CKD2	Next visit due: 27/02/2020	✖
500-0001	P	M-01/2010	Glomerulopathy (Alport-Patient)	CKD3	Next visit due: 10/01/2019	✖

Figure 5: Data entry

By clicking on "data entry", the user can enter patient data in the registry.

1. The first step to follow in order to record the patient's data is to click on "**add a new patient**".
2. The "red cross" permit the user to delete the patient entry.
3. The "Patient code" is unique and is automatically generated by the system whenever a new patient is correctly registered in the registry. The patient code consists of 7 numbers: the first 3 numbers correspond to the centre code and are identical for all patients registered in the same ERKnet centre.
4. Indicates the sex and date of birth of the patient.
5. Indicates the group of rare kidney diseases related to the patient's pathology. This box also indicates whether the patient has been registered in subregistries.
6. Patient's CKD stage



- Alerts the user when the next update is due. The colour green indicates that the patient is correctly registered, yellow or red warning the user the patient data must be updated or completed.

4.1. Add a new patient

The screenshot shows the ERKReg 'Add a new patient' form. The header includes the ERKReg logo and the text 'The European Rare Kidney Disease Registry'. A sidebar on the left contains navigation links: 'Registry start page', 'Data entry', 'Admin: Select Center', 'Export data', 'Export dRTA data', 'Export Alport data', 'KPI Monitoring', 'Enrolment by center', 'Downloads', 'Administration Area', 'EUPID-TEST', and 'ERKNet Home Page'. The main form area has a 'Patient-ID' field with a callout '1' and a 'Return to patient list' button. Below this is a 'Basic data entry not completed!' warning. The 'Participation in Affiliated Registries' section has two checkboxes: 'Include patient also in dRTA Registry' and 'Include patient also in italian Alport Registry' (with a red note '(under construction - do not check yet!)'). The 'Center unit' is a dropdown menu with callout '3'. The 'ERKNet Registry' section has a 'Date of informed consent' field (dd/mm/yyyy) with callout '4' and three consent checkboxes: 'Consent to data being shared for clinical care', 'Consent to coded data being included in one or more ERN database or registry', and 'Consent to being contacted about research projects', with callout '5'.

Figure 6: Data entry

- Patient ID will be automatically generated by the System after saving. Produce a excel document in order to save the Name, Surname, date of birth, date of informed consent of the patient, personal Patient ID of the patient (generated after that all the data will be correctly saved).



	A	B	C	D	E	F	G	H	I
1	Name	Surname	DOB	date of informed consent	Patient ID				
2	MARIO	ROSSI	16.02.2016	19.05.2019	500-0001				
3									
4									

Figure 7: Example of Excel table with the data of patients

2. If the patient has a rare kidney disease for which a subregister has been established, select the corresponding subregister. The Alport sub-register is currently only available for Italian centres.
3. Indicate if your center is a pediatric or adult unit. If the centre is only pediatric or only for adult, the system will automatically select the correct choice.
4. Enter the date of informed consent. This is mandatory. **Is not permitted to register patients who have not signed the document.**
5. Insert the statements signed in the patient's consent, choosing between "yes" or "no". To be able to enter the patient in the register, all 3 statements must be "yes".



Basic data 6

Sex

Date of birth (mm/yyyy)

Ethnicity

Date of first symptoms (mm/yyyy)
(leave field empty if unknown)

Date of first presentation to center (dd/mm/yyyy)

Renal diagnosis established? Yes 7

Primary renal diagnosis 8 (OC: 0)

Select diagnosis... OR Diagnosis by gene... OR Enter OrphaCode... OR Search diagnosis name...

Does the patient have a second renal diagnosis? No

Diagnostic survey 9

When was the diagnosis considered confirmed? (dd/mm/yyyy)

How was the diagnosis established?
(Tick all that apply)

(1) Please check even if results negative or pending

☐ Clinical history
☐ Positive family history
☐ Clinical examination
☐ Biochemical evaluation
☐ Immunological evaluation 10
☐ Hematological evaluation
☐ Imaging
☐ Kidney biopsy
☐ Skin biopsy
☐ Genetic screening (1)
☐ Other methodologies

☐ Completed 11

Check this box for full data validation and completion of basic data!
Otherwise proceeding with visit data is not possible.

Figure 8: Data Entry

6. Fill the Basic data about the patient in.
7. If the kidney diagnosis has not been established, mark "no". The user can change the information at any time (even after saving the data).
8. "Primary renal diagnosis" can be chosen through 4 different search bars:
 - "Select diagnosis": the search is made through Orphanet catalogue, choosing in hierarchical order the group of the disease up to the defined pathology.



- **“Diagnosis by gene”**: the search for rare kidney disease is done by typing in the search bar the name of the mutated gene that caused the disease.
 - **“Enter ORPHA code”**: the search for rare kidney disease is done using the code Orphanet
 - **“Search diagnosis name”**: the search is done by directly typing the name of the rare kidney disease into the search bar.
- Depending on the disease, the diagnosis can be confirmed at different times: sometimes it can be combined with genetics, in other cases such as cystinuria, the doctor is able to make a diagnosis almost immediately without the need for genetic testing.
 - Proceed by clicking on the clinical exams that enabled you to make a diagnosis. Additional specific questions will be automatically added by the system depending by the disease.
 - Once finished, click on "completed". Patient registration is now finished, the system will generate automatically a patient ID code (as showed below). Basic data entry is completed, you can enter the initial visit entry by clicking on “initial visit entry”.

You are logged in as admin_bassanese

Logout

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Data entry

Admin: Select Center

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Patient-ID

Dataset created: 07/06/2019

500-0007

Return to patient list

Basic data entry is completed - please enter the initial visit entry now!

Participation in Affiliated Registries

Include patient also in dRTA Registry ☐

Include patient also in italian Alport Registry ☐ (under construction - do not check yet!)

Center unit: Pediatric

ERKNet Registry

Date of informed consent: 19/05/2019 (dd/mm/yyyy)

Consent to data being shared for clinical care: Yes

Consent to coded data being included in one or more ERN database or registry: Yes

Consent to being contacted about research projects: Yes

Figure 9: Data entry completed

5. Initial visit



You are logged in as **admin_bassanese**

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[Admin: Select Center](#)

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Center: Wiesenbach, Test Center external

Patient filter order by: [Patient ID \[descending\]](#)

[\[Both units\]](#) [\[All visits\]](#) [\[All CKD stages\]](#) [\[All treatments\]](#) [\[All registries\]](#)

[\[All disease groups / diagnoses\]](#) [\[Family filter OFF\]](#)

Please check a patient below or [Add a new patient...](#)

500-0007	P	F-04/2017	Tubulopathy	
				Click to enter initial visit!
Basic data	Add visit	Termination	Previous visits:	
500-0006	P	M-01/2017	Metabolic nephropathy	CKD3 Next visit due: 05/05/2020
500-0005	P	M-01/2008	Glomerulopathy (Alport-Patient)	CKD5 Next visit due: 01/05/2020
500-0004	P	M-01/2010	Glomerulopathy	CKD4 Next visit due: 01/04/2020
500-0002	A	F-01/1975	Glomerulopathy (Alport-Patient)	CKD2 Next visit due: 27/02/2020
500-0001	P	M-01/2010	Glomerulopathy (Alport-Patient)	CKD3 Next visit due: 10/01/2019

Figure 10: Data entry menu page

1. Click it for modifying "basic data" and to come back to the previous screen
2. Click for entering the initial visit
3. If the patient should drop out from the registry because of his willing or in case of death
4. To enter the initial visit

5.1. Add the initial visit

The date of the initial visit may coincide with the date of the signature of the informed consent but cannot older than one month. (see figure 11 below)

Add the patient data as requested by the System. Additional specific questions will be automatically added by the system depending by the disease.



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[ERKNet Home Page](#)

Patient

500-0007 (F-04/2017)

Visit Date

19/05/2019

(dd/mm/yyyy)

Age at visit

2.1 y

Current treatment modality



Anthropometric features

Height

cm

Height SDS

Weight

kg

BMI

BMI SDS

Blood pressure

(mean of last 2-3 measurements if measured more than once in past 12 months)

/ mm Hg

Biochemical features

Serum creatinine

mg/dl

or convert:

µmol/L

Estimated GFR

[Save](#)

[Return to patient list](#)

Figure 11: Initial visit

The screenshot shows the ERKReg patient data entry form for patient 500-0007 (F-04/2017). The form is titled "Patient" and includes a "Visit data created: 07/06/2019" timestamp. The "Visit Date" is set to 19/05/2019 (dd/mm/yyyy) and the "Age at visit" is 2.1 y. The "Current treatment modality" is set to "Conservative". A white modal box with the text "Saving successful!" is displayed over the form. The "Anthropometric features" section includes fields for Height, Weight, Height SDS, BMI, and BMI SDS. The "Blood pressure" section includes a field for Blood pressure (mean of last 2-3 measurements if measured more than once in past 12 months). The "Biochemical features" section includes fields for Serum creatinine, Estimated GFR, CKD1, and a "or convert:" option for µmol/L. The "Save" button is visible at the bottom left, and the "Return to patient list" button is at the bottom right. A "Delete visit:" button with a red 'x' icon is at the bottom right.

Patient **500-0007 (F-04/2017)**

Visit data created: 07/06/2019

Visit Date: 19/05/2019 (dd/mm/yyyy) Age at visit: 2.1 y

Current treatment modality: Conservative

Anthropometric features

Height: cm Height SDS:

Weight: kg BMI:

BMI SDS:

Blood pressure: / mm Hg

(mean of last 2-3 measurements if measured more than once in past 12 months)

Biochemical features

Serum creatinine: mg/dl or convert: µmol/L

Estimated GFR: CKD1:

[Save](#) [Return to patient list](#)

Delete visit:



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Figure 12: Initial visit successfully saved

6. End of patient registration process

The patient was successfully saved as indicated in the green colour message “next visit due: 19/05/2019”. The user will add a new visit in the data suggested by the system.

The screenshot shows the ERKReg web application interface. On the left is a sidebar menu with options: Registry start page, Data entry, Admin: Select Center, Export data, Export dRTA data, Export Alport data, KPI Monitoring, Enrolment by center, Downloads, Administration Area, EUPID-TEST, and ERKNet Home Page. The main content area shows the user is logged in as admin_bassanese. The center is set to Wiesenbach, Test Center external. There are filters for Patient ID, Both units, All visits, All CKD stages, All treatments, All registries, All disease groups / diagnoses, and Family filter OFF. A table lists patients with columns for ID, status, date, disease, CKD stage, next visit due, and a delete icon. The first patient (500-0007) has a next visit due of 19/05/2020. The second patient (500-0006) has a next visit due of 05/05/2020. The third patient (500-0005) has a next visit due of 01/05/2020. The fourth patient (500-0004) has a next visit due of 01/04/2020. The fifth patient (500-0002) has a next visit due of 27/02/2020. The sixth patient (500-0001) has a next visit due of 10/01/2019.

Patient ID	Status	Date	Disease	CKD Stage	Next visit due	Action
500-0007	P	F-04/2017	Tubulopathy	CKD1	Next visit due: 19/05/2020	
500-0006	P	M-01/2010	Metabolic nephropathy	CKD3	Next visit due: 05/05/2020	
500-0005	P	M-01/2008	Glomerulopathy (Alport-Patient)	CKD5	Next visit due: 01/05/2020	
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500-0001	P	M-01/2010	Glomerulopathy (Alport-Patient)	CKD3	Next visit due: 10/01/2019	

Figure 13: Data entry menu



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7. Downloads

You are logged in as **admin_bassanese**

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[ERKNet Home Page](#)

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Metabolic nephropathies	62	60	15	8	77	68
Thrombotic microangiopathies	53	46	9	9	62	55
CAKUT and ciliopathies	202	193	6	6	208	199
AD structural disorders	126	122	63	63	189	185
TOTAL	877	843	307	284	1184	1127
Pediatric CKD and dialysis	707	706				
Pediatric transplantation	162	162				

Figure 14: Registry start page

ERKNet
The European Rare Kidney Disease Reference Network

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- Meeting Presentations
- Center Logos
- Informed Consent Templates
- Renal OrphaCode List

You are logged in as **admin_bassanese**

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Tweets by @EuRefNetwork

ERKNet
@EuRefNetwork

#suPAR levels independently predict #renal function decline and incident #ESKD in patients with #ADPKD
jasn.asnjournals.org/content/early/...

Soluble Urokinase Plas...
Soluble urokinase plasm...
jasn.asnjournals.org

Figure 15: Downloads page

7.1. Informed consent template

In this section are available the informed consent in all the languages of the European Community.

THIS CONSENT FORM MAY BE USED FOR SHARING DATA WITH THE FOLLOWING ERN(S)
(To be completed by the health care professional signing below)

1

PATIENT DETAILS

First Name: Surname:

Date of Birth:
 D D M M Y Y Y Y

ID number:

2

Please tick the box that applies:

☐ I am the patient ☐ I am the parent/guardian of the patient ☐ I have power of attorney

<div style="border: 1px solid green; padding: 10px; background-color: #e6ffe6;"> <p>I CONSENT to my de-identified data being shared in ERN(s) for my CARE</p> <p>I understand that my data will be shared with healthcare professionals in the ERN (s) so that they may work together to support my care.</p> <p>Signature _____ Date _____</p> </div>	<div style="border: 1px solid red; padding: 10px; background-color: #ffe6e6;"> <p>I DO NOT CONSENT to my data being shared in ERN(s) for my CARE</p> <p>I understand that this means the ERN(s) cannot be consulted to support my care.</p> <p>Signature _____ Date _____</p> </div>
<div style="border: 1px solid green; padding: 10px; background-color: #e6ffe6;"> <p>I CONSENT to my de-identified data being included in one or more ERN database or registry.</p> <p>Signature _____ Date _____</p> </div>	<div style="border: 1px solid red; padding: 10px; background-color: #ffe6e6;"> <p>I DO NOT CONSENT to my data being included in an ERN database or registry.</p> <p>Signature _____ Date _____</p> </div>
<div style="border: 1px solid green; padding: 10px; background-color: #e6ffe6;"> <p>I WOULD LIKE TO BE CONTACTED about research. I will decide if I consent to my data being used for a specific project if I am contacted.</p> <p>Signature _____ Date _____</p> </div>	<div style="border: 1px solid red; padding: 10px; background-color: #ffe6e6;"> <p>I DO NOT WANT TO BE CONTACTED about my data being used in research.</p> <p>Signature _____ Date _____</p> </div>

3

TREATING PHYSICIAN or PERSON AUTHORISED TO WITNESS CONSENT

Name: Position: Date:

Figure 16: Informed consent template

1. Indicate the ERN name, in this case ERKNet and eventually sub-registries (dRTA)



ERKReg

The European Rare Kidney Disease Registry



Figure 17: Example

2. Complete with the Patient ID automatically generated by the system (once the patient is successfully registered – for more info see figure 6 and 11)
3. Complete with the name of the treating physician who has gathered the Consent.

7.2. Renal Orpha code list

The list contains all the kidney diseases in the registry and in order to clarify the user which diseases can be entered and which not, it must be consulted before starting the registration process.