

The European Rare Kidney Disease Registry

Bartter – Gitelman Syndromes Sub-registry user manual

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INTRODUCTION

The Bartter Gitelman (BG) sub-registry is one of several sub-registries collection disease specific information in ERKReg and this document provides a step-by-step user manual to enter a new patient and add the patient data.

Once logged-in to ERKReg, please select the Data Entry option from the left-side menu to enter the Patients Registry page (Figure 1).

The Patients Registry page displays the existing patients from your center in ERKReg with the current CKD classification and the next scheduled visit. You may also use the top section of the page to filter and identify patients. Of special note is the option to filter patients by association to a sub-registry.

Patients Registry

Center: Wiesenbach, Test Center external

Patient filter order by: Patient ID [descending]

[Both units] [All visits] [All CKD stages] [All treatments] Bartter

[All disease groups / diagnoses]

[Family filter OFF]

Note: If a patient does not appear in the patient list after changes, please check your filter settings.

Please check a patient below or

500-0053	P	M-09/2023	Tubulopathy (Bartter/Gitelman-Patient)		Click to enter initial visit!	x
500-0032	P	F-12/2005	Tubulopathy (Bartter/Gitelman-Patient)	CKD3	Next visit due: 14/09/2024	x
500-0023	P	F-10/2015	Tubulopathy (Bartter/Gitelman-Patient)	CKD1	Next visit due: 04/04/2024	x
500-0017	P	M-11/2021	Tubulopathy (Bartter/Gitelman-Patient)		Click to enter initial visit!	x

FIGURE 1: ERKReg data entry page

When a patient line is selected, the patient menu appears (Figure 2), which allows to modify the basic patient data, add or modify visit data, and medications.

500-0053	P	M-09/2023	Tubulopathy (Bartter/Gitelman-Patient)	Click to enter initial visit!	x
Basic data Add visit Termination Medications Previous visits:					

FIGURE 2: Options available upon selection of a BG sub-registry patient.

BASIC DATA

When a new patient is added to the registry, the basic data module is presented, where you are required to enter the center unit, and can select to include the patient in the BG sub-registry (Figure 3).

[Return to patient list](#)

Patient-ID

Will be generated after saving

Basic data entry not completed!

Patient also registered for:

- | | |
|--|---|
| dRTA Subregistry | ☐ |
| Italian Alport Subregistry | ☐ |
| Childhood-onset SLE Subregistry | ☐ |
| Cystinuria Subregistry (Eurocys) | ☐ |
| Bartter/Gitelman Subregistry | ☒ |
| esCapeKD Subregistry and Cohort Study | ☐ |
| CompCure C3G/MPGN Subregistry and Cohort Study | ☐ |
| IgA Nephropathy / IgA Vasculitis Subregistry | ☐ |
| ADTKD Subregistry | ☐ |
| ANCA Vasculitis Subregistry | ☐ (under construction - do not check yet!) |

Center unit

Note: Center unit is not changeable after saving.
Please enter with care!

FIGURE 3: Adding a new patient to the BG sub-registry.

Please note, for existing patients in the registry, you may modify the basic data by selecting the “Basic data” button (see Figure 2), you may then add them to the BG sub-registry. After which, disease specific fields will be presented (Figure 4).

For each patient in the registry, basic information is collected - including the date of consent, the patient background and information regarding the disease diagnosis (Figure 4).

ERKNet Registry

Date of informed consent (dd/mm/yyyy)

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

Consent to being contacted about research projects or clinical trials ☐

Consent to pseudonymized data being shared to support commercial projects aimed at improving healthcare. [\[info\]](#) ☐

Consent to pseudonymized data being shared with researchers outside the European Union. [\[info\]](#) ☐

Note:

• Please use the [updated consent form](#), which contains the previous two items.

Basic data

Sex

Date of birth (mm/yyyy)

Ethnicity

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

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

Renal diagnosis established? Yes ☐

Primary renal diagnosis (OC: 0)

Select diagnosis...

OR

Diagnosis by gene...

OR

Enter OrphaCode...

OR

Search diagnosis name...

Note: To record a syndromic form of CAKUT, please assign its non-syndromic form first. Only then it will be possible to specify the syndromic form.

Does the patient have a second renal diagnosis? No ☐

Diagnostic survey

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

Which methods were used to establish the diagnosis?

(Tick all that apply)

(¹) Please check even if results negative or pending

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

FIGURE 4: Basic information collected for all registry patients.

For sub-registry patients, additional disease specific fields are collected, the additional fields for BG sub-registry are depicted in Figure 5.

Prenatal history

Number of weeks of gestation: weeks

Prenatal manifestation:

Birth weight grams

Acute renal failure in neonatal period

Family history

Family members affected?

Height father cm

Height mother cm

Clinical presentation at time of diagnosis

Polydipsia (Thirst) / Polyuria	
Failure to thrive	
Growth retardation	
Salt craving	
Muscle weakness	
Muscle cramps / Tetany / Carpopedal spasms	
Paresthesia	
Joint pain/Chondrocalcinosis	
Cardiac arrhythmia	
Ataxia	
Hearing impairment/Sensorineural deafness	
Incidental discovery of electrolyte abnormalities	
Seizure(s)	
Other	

Biochemical features at time of first presentation

Serum creatinine	mg/dl	or convert:	μmol/L
Estimated GFR	0 ml/min/1.73m ²		

Blood parameters

Hemoglobin	g/dl	or convert:	mmol/l
Cystatin C	mg/l		
Serum bicarbonate	mmol/L		
Serum inorganic phosphorus	mmol/L	or convert:	mg/dl
Potassium	mmol/L	or convert:	mg/dl
Sodium	mmol/L		
Chloride	mmol/L		
Calcium	mmol/L	or convert:	mg/dl
Magnesium	mmol/L	or convert:	mg/dl
Parathyroid hormone (PTH)	pmol/L	or convert:	pg/mL
Alkaline phosphatase	U/L		
Plasma osmolality	mosmol/L		
Renin, direct	ng/L	or convert:	mmol/L
Plasma renin activity (PRA)	μIU/mL		
Aldosterone	ng/dL	or convert:	pmol/L

Urine parameters

Creatinine	mmol/L	or convert:	mg/dl
Calcium	mg/dl	or convert:	mmol/L
Osmolality	mosmol/L		
Albuminuria			
Proteinuria			

(please choose best available measurement from dropdown menu, prioritizing from top to bottom)

FIGURE 5: BG sub-registry specific data fields collected in the sub-registry.

ADD VISIT

Once the basic data is entered, you will be able to add a visit for the patient. It is mandatory to fill the date of the visit, the current treatment modality, the height, the weight, the blood pressure and the serum creatinine (see Figure 6). If the serum creatinine was measured in $\mu\text{mol/L}$ rather than in mg/dl , it is possible to directly make the conversion using the conversion field.

Please note that data entered into mg/dl will not be converted into $\mu\text{mol/L}$ and the data is only saved using the SI units.

Patient 500-0053 (M-09/2023)

Visit Date	10/06/2025 (dd/mm/yyyy)	Age at visit	1.8 y
Current treatment modality			
Anthropometric features			
Height	cm	Height SDS	
Weight	kg	BMI	
Blood pressure (mean of last 2-3 measurements if measured more than once in past 12 months)	/ mm Hg	BMI SDS	
Biochemical features			
Serum creatinine	mg/dl	or convert:	$\mu\text{mol/L}$
Estimated GFR			

FIGURE 6: BG sub-registry entering visit data.

Additional biochemical parameters can then be added, if the measurements were performed (Figure 5). If the measurements were not conducted, please leave the fields empty (Figure 7). When relevant, additional conversion fields are available to convert from molar units to SI units.

Clinical features

Diarrhea	
Fatigue, weakness (severe)	
Abdominal pain	
Sensorineural hearing loss	
Polydipsia (Thirst) / Polyuria	
Failure to thrive	
Salt craving	
Muscle weakness	
Muscle cramps / Tetany / Carpopedal spasms	
Paresthesia	
Joint pain/Chondrocalcinosis	
Cardiac arrhythmia	
Ataxia	
Seizure(s) [info]	
Other	

Blood parameters

Hemoglobin	g/dl	or convert: mmol/L
Cystatin C	mg/l	
Serum bicarbonate	mmol/L	
Serum inorganic phosphorus	mmol/L	or convert: mg/dl
Potassium	mmol/L	or convert: mg/dl
Sodium	mmol/L	
Chloride	mmol/L	
Calcium	mmol/L	or convert: mg/dl
Magnesium	mmol/L	or convert: mg/dl
Parathyroid hormone (PTH)	pmol/L	or convert: pg/mL
Alkaline phosphatase	U/L	
Plasma osmolality	mosmol/L	
Renin, direct	ng/L	or convert: mmol/L
Plasma renin activity (PRA)	µIU/mL	
Aldosterone	ng/dL	or convert: pmol/L

Urine parameters

Creatinine	mmol/L	or convert: mg/dl
Calcium	mg/dl	or convert: mmol/L
Osmolality	mosmol/L	
Albuminuria		
Proteinuria		

(please choose best available measurement from dropdown menu, prioritizing from top to bottom)

Sonographic features

Are sonographic features available for this visit?
(Presence of renal stones, cysts, medullary nephrocalcinosis)

No medications have been recorded for this patient.

The medication history can be reviewed by clicking on the following [link](#) (will open in new tab)

Even if the patient has no recorded medications due to not receiving any, please use the corresponding button to validate the medication history.

[Save](#)

[Return to patient list](#)

FIGURE 7: BG sub-registry entering visit data.

TERMINATION

Patients can be terminated if the follow-up does not take place anymore or if the patient passes away (Figure 8).

If the patient care is transferred to another center – please contact us using the contact information found at the end of the manual, we will transition the patient to the new center and assign them with a new patient id.

Please note - termination does not delete the patient data from the database.

Center: Wiesenbach, Test Center external

Patient-ID 500-0053

Reason for end of follow-up



- Loss of follow-up (including transfer to non-ERKNet center)
- Patient death
- Transition to adult unit
- Administrator only:
- Transition to other center

[Save](#)

[Return to patient list](#)

FIGURE 8: BG sub-registry entering visit data.

MEDICATIONS

Under the medications module, specific medications usage information is collected (Figure 9). New medications can be added and existing data can be modified (by clicking on medication name) to reflect the current treatment of the patient.

For each drug, specify the prescribed dosage, route of admission, frequency of usage and the patient weight at the time of prescription (the weight is used to calculate the dosage/kg/day field displayed in the table in Figure 9).

For ongoing treatments, the stop date should be left empty.

If a change in dosage occurred, please enter a stop date for the current dosage and readd the drug using the new dosage.

Patient **500-0053 (M-09/2023)**

Medication history

= ongoing medication
 = terminated medication
 = incomplete medication

Medication	Start date	Single dose	Frequency	= dose/kg/day	Stop date	
Magnesium hydroxide	24/10/2023	2 mmol	1x /	0.029 mmol/kg/day		New dose ✖

Click on a medication to edit or add a new medication.

To submit a **correction** on the dosage, frequency, or stop date, click on the medication name. This will overwrite the previous information.

To record a **change of dosage** of a medication, click on the medication name. The dosage from the previous period will be preserved. This option is only available for treatments that are ongoing.

To add a medication, you can either click on the **+** button or the **Add medication** button.

Note: If you cannot find the medication, you can click on **Search** to find it.

By clicking on the **"Validate medication history"** button, you will validate the medication history for this patient, and the system will check if the medication history is necessary.

For example:

- If all known medications are entered.
- If the patient is not receiving any medication.

Entering a new medication or changing an existing one will automatically update the validation date.

Please review the medication history before clicking on the **Validate medication history** button.

Medication history was validated on 24/10/2023

This validation feature helps distinguish between cases where the medication table has not been updated because the patient does not receive any of the recorded medications, and cases where it has not been updated due to oversight.

[Return to patient list](#)

FIGURE 9: BG sub-registry entering medication.

In case of a missing medication – please contact us by email using the contact information found at the end of the manual.

CONTACT

If you have any issue, please contact the ERKReg project manager: contact@erknet.org