ERKReg
The European Rare Kidney Disease Registry

IgAN / IgAV Subregistry User Manual

This report is part of the project '777304 / ERK-REG', which has received funding from the EU Health Programme (2014-2024).

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INTRODUCTION

The IgAN / IgAV subregistry is a subregistry of ERKReg. 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 subregistry.

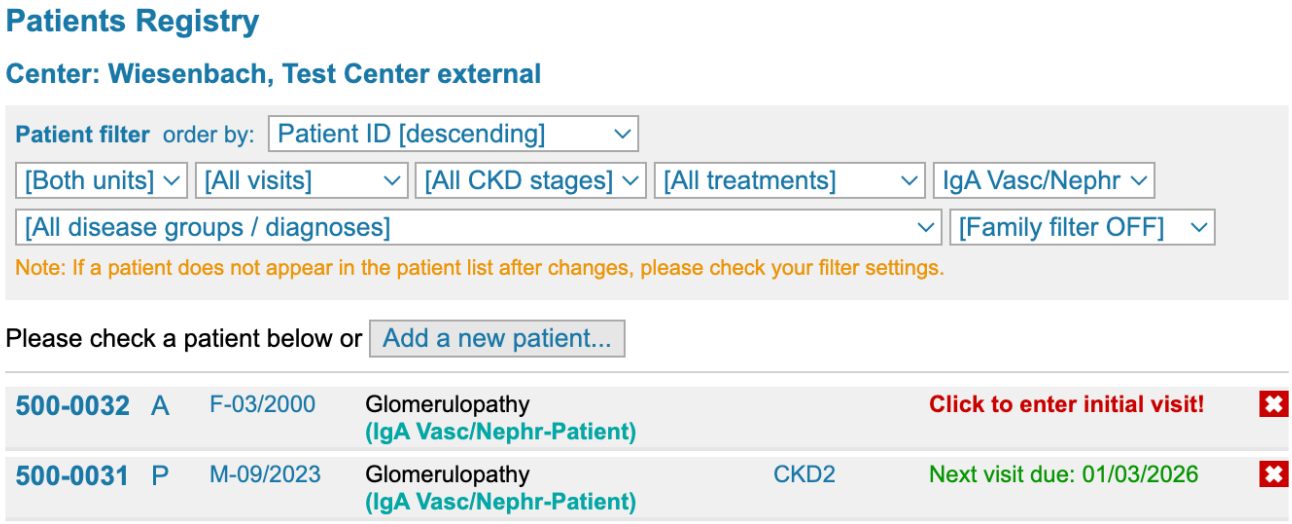

Figure 1: ERKReg data entry page

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, medications and extracorporeal therapies.

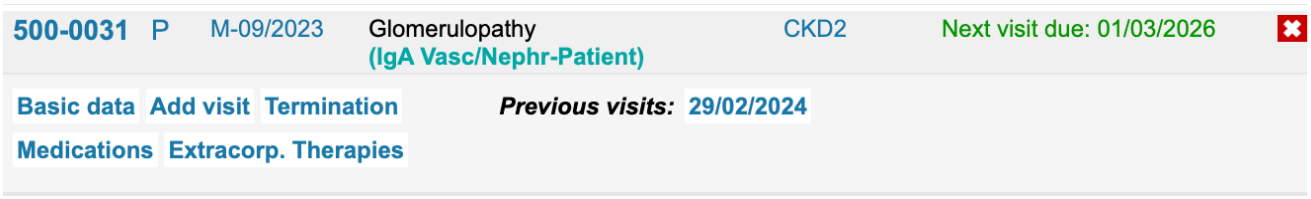

Figure 2: Options available upon selection of an IgAN / IgAV subregistry patient.

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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 IgAN/IgAV subregistry (Figure 3).

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 IgAN/IgAV subregistry. After which, disease specific fields will be presented (Figure 4).

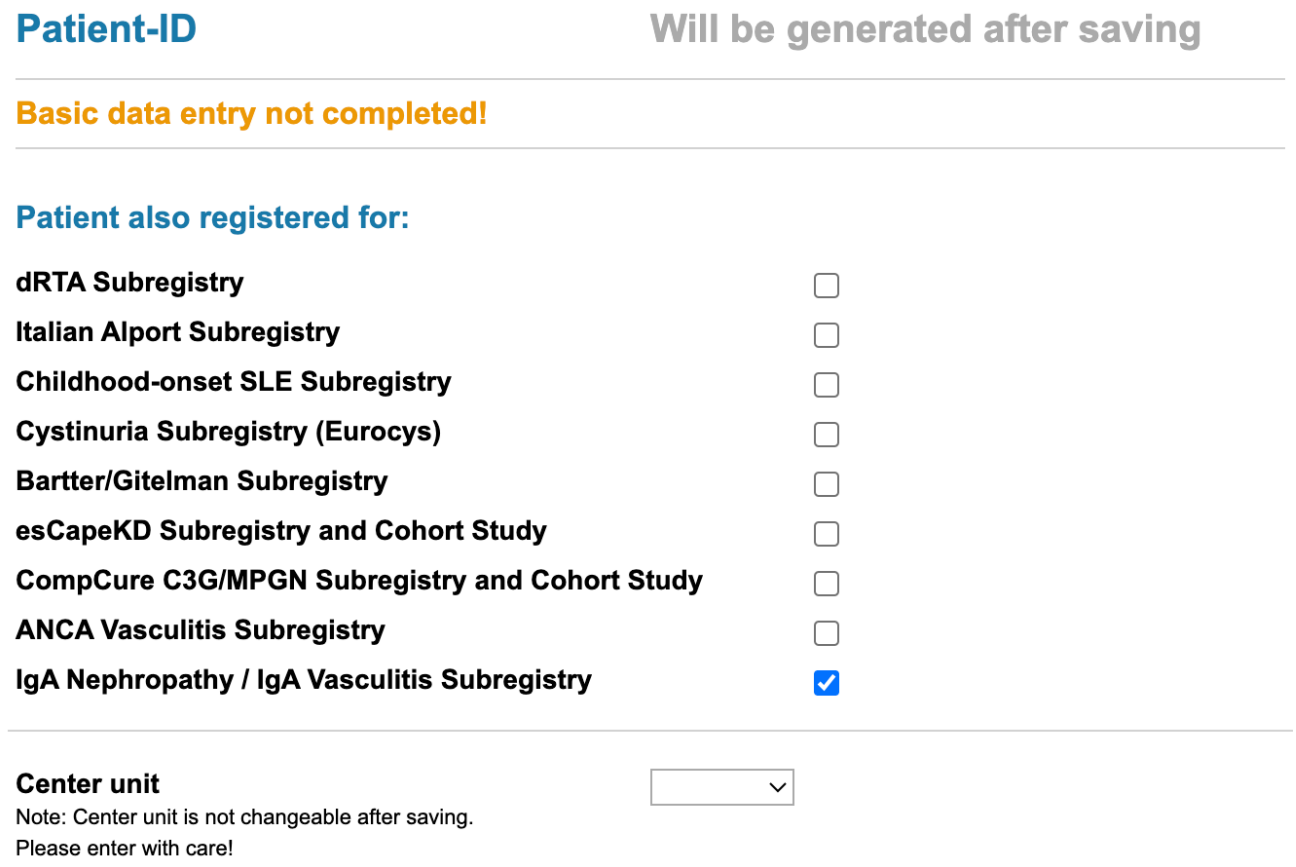

Figure 3: Adding a new patient to the IgAN / IgaV subregistry.

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).

For subregistry patients, additional disease specific fields are collected, the additional fields for IgAN/IgAV are depicted in Figure 5.

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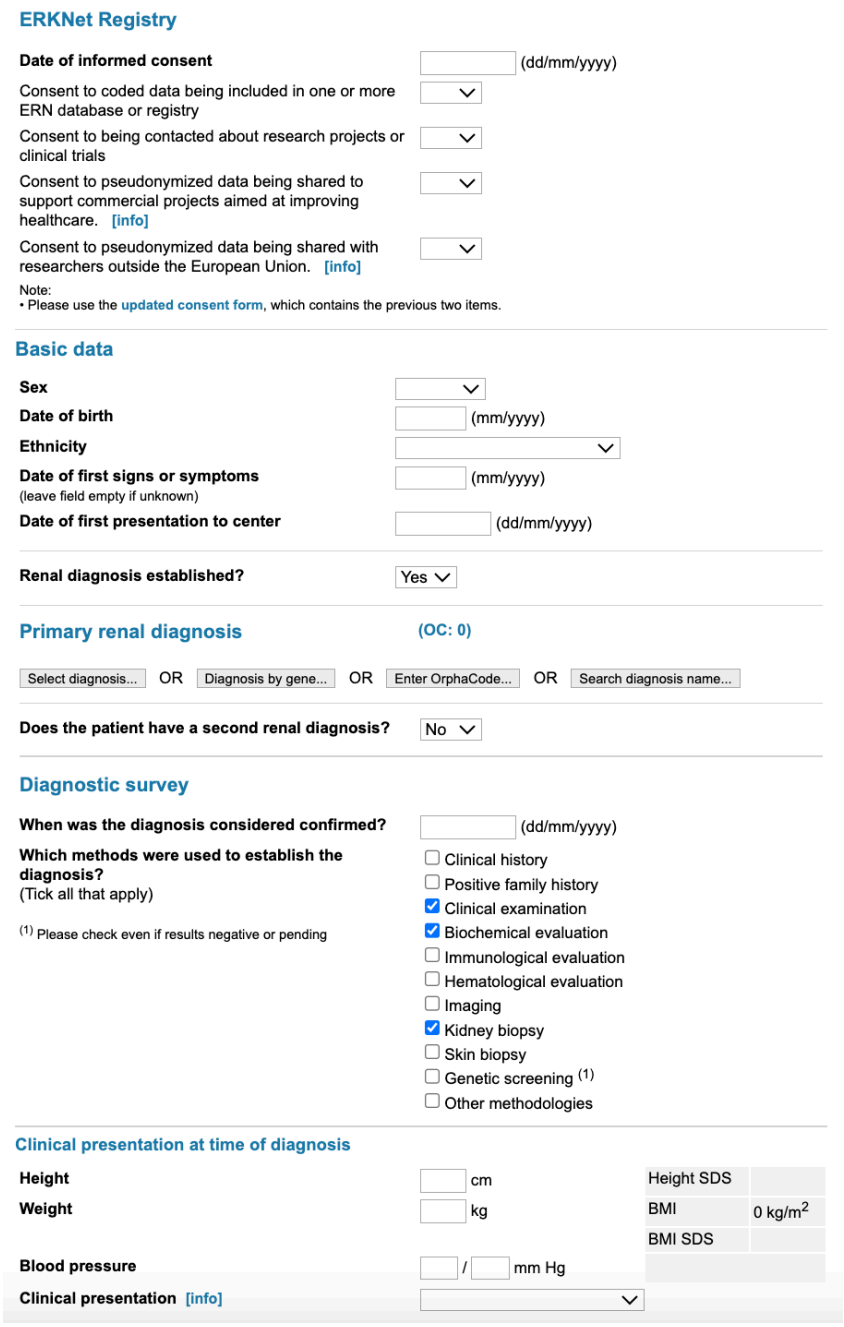

Figure 4: Basic information collected for all registry patients.

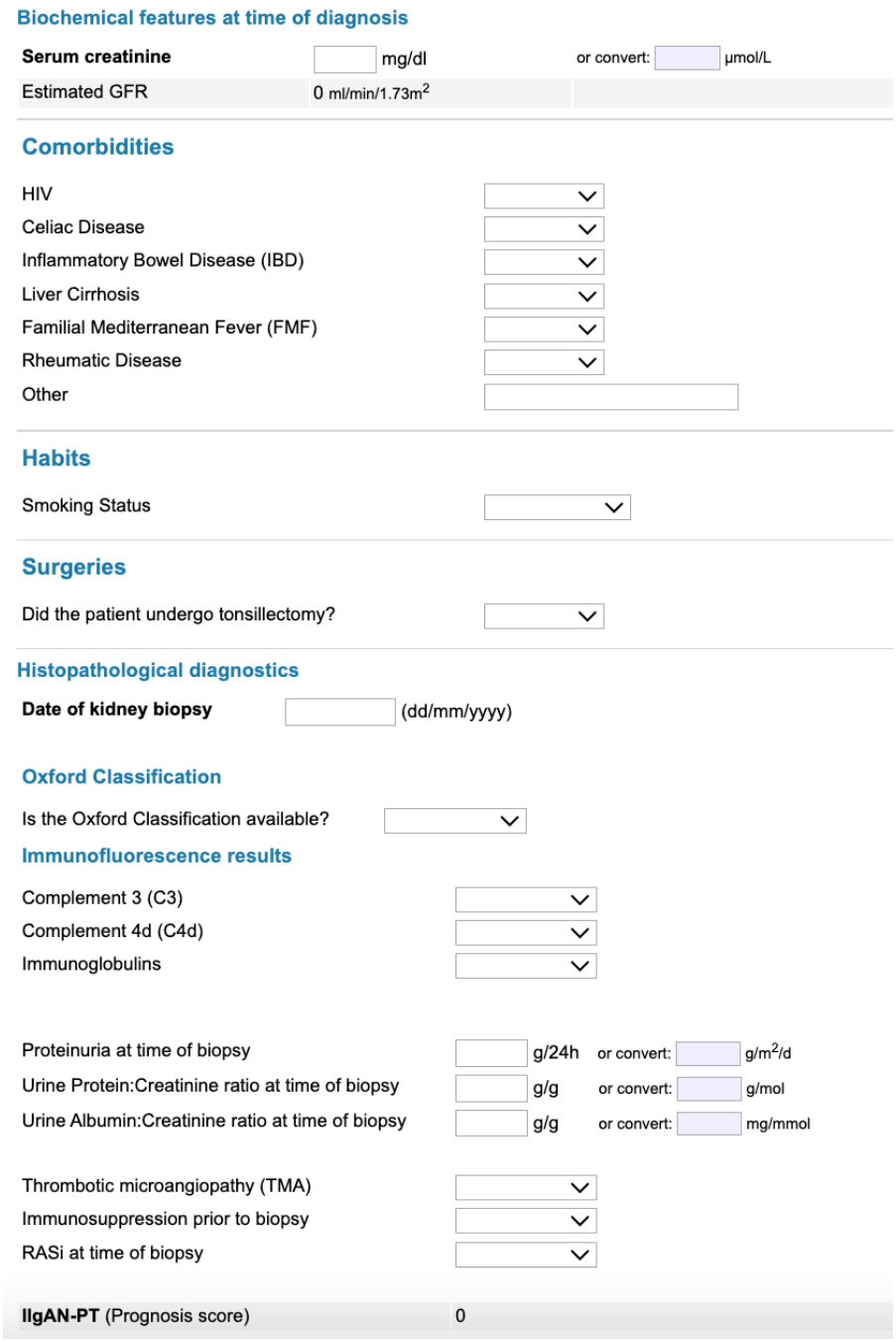

Figure 5: IgAN / IgAV specific data fields collected in the subregistry.

ADD VISIT

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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 creatine was measured in µmol/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 µmol/L and the data is only saved using the SI units.

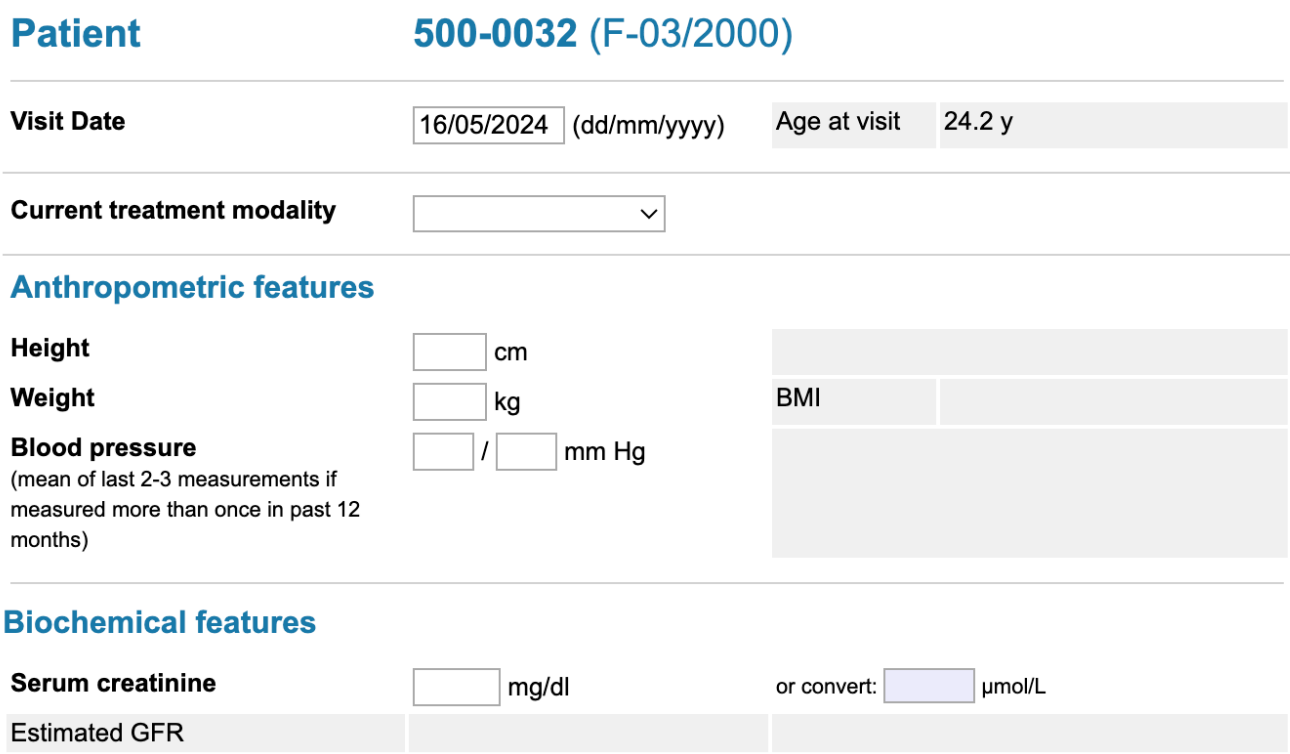

Figure 6: Entering visit data information.

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.

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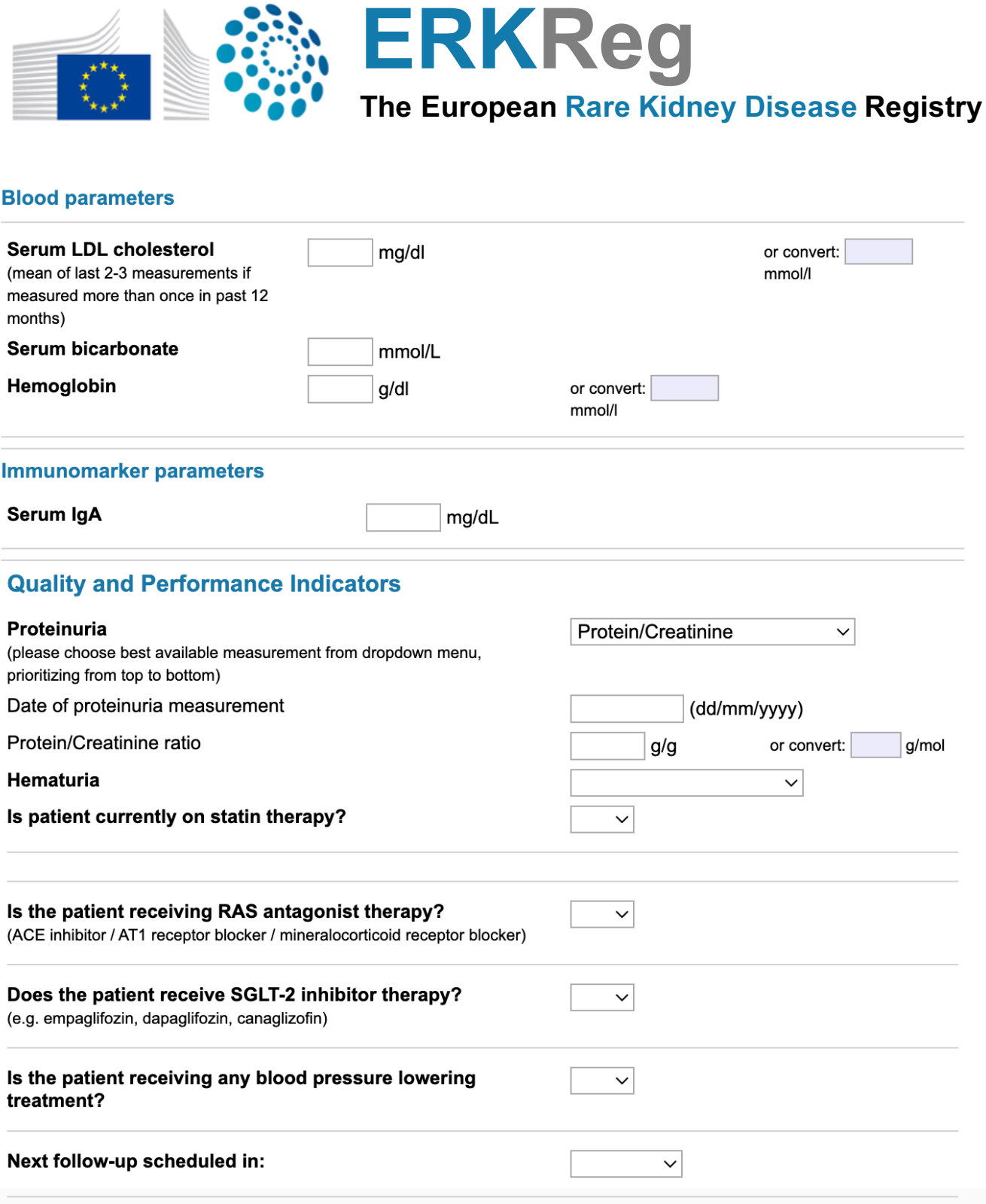

Figure 7: Biochemical parameters for patients enrolled in the IgAN / IgAV subregistry.

At the end of the visit, please enter the next scheduled follow-up visit (as depicted in Figure 7). Please use the following instructions for the next scheduled visit interval:

- 3 Months – Patients with a rapidly-progressive disease course (defined as ≥50% decline in eGFR over three months or less) or first visit after transplantation.

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- 6 Months – Patients within the first year of diagnosis or first visit after the initiation of a new medication, or patients with a ≥25% decline in eGFR over a year or less or an increase of 0.5 in urine protein:creatinine over a year or less.
- 1 Year – The default interval.
- 2 Years – IgAV patients with eGFR > 90 ml/min/1.72m2 and at least two years without significant proteinuria (defined as urine protein:creatinine < 0.2 for children or < 0.5 for adults), hematuria or clinical features suggesting of IgAV (palpable purpuric rash, arthralgia/arthritis or episodic abdominal pain not otherwise explained).

If a biopsy was performed, additional fields about the biopsy information are presented – including the Oxford MEST-C classification (for both IgAN and IgAV) and additional parameters required for the IIgAN-PT prognosis score (Figure 8).
Please note - the score is only calculated once all fields are filled in.

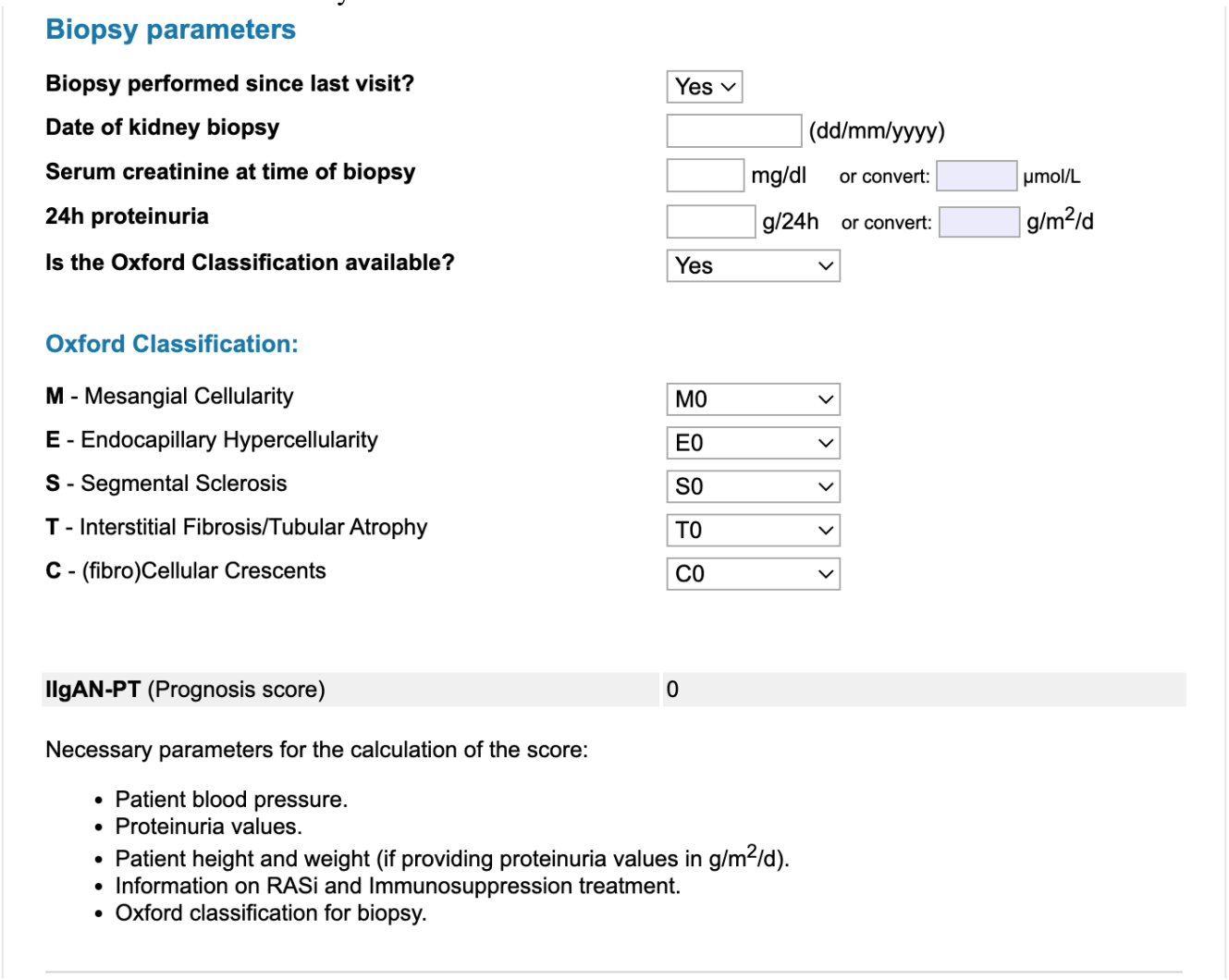

Figure 8: Biopsy information for patients in the IgAN / IgAV subregistry.

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TERMINATION

Patients can be terminated if the follow-up does not take place anymore or if the patient passes away (Figure 9).
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.

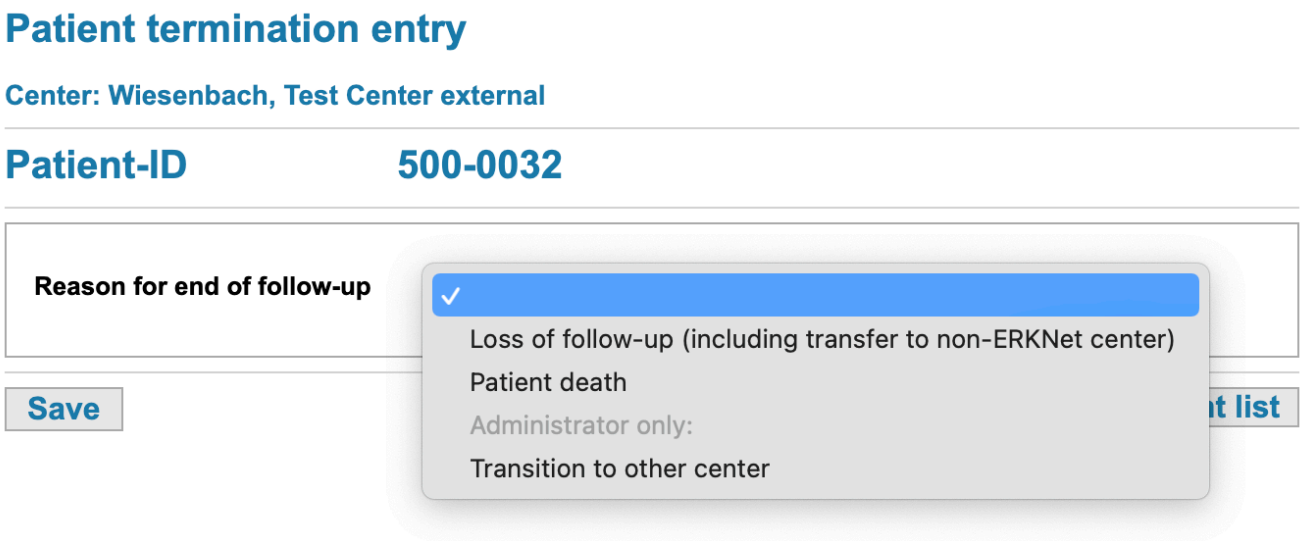

Figure 9: Patient termination entry

EXTRACORPORAL THERAPIES

In extracorporal therapies, you may enter information about specific treatment modalities: plasmapheresis and renal replacement therapies (Figure 10).
By clicking on an existing therapy, you may modify the saved information.

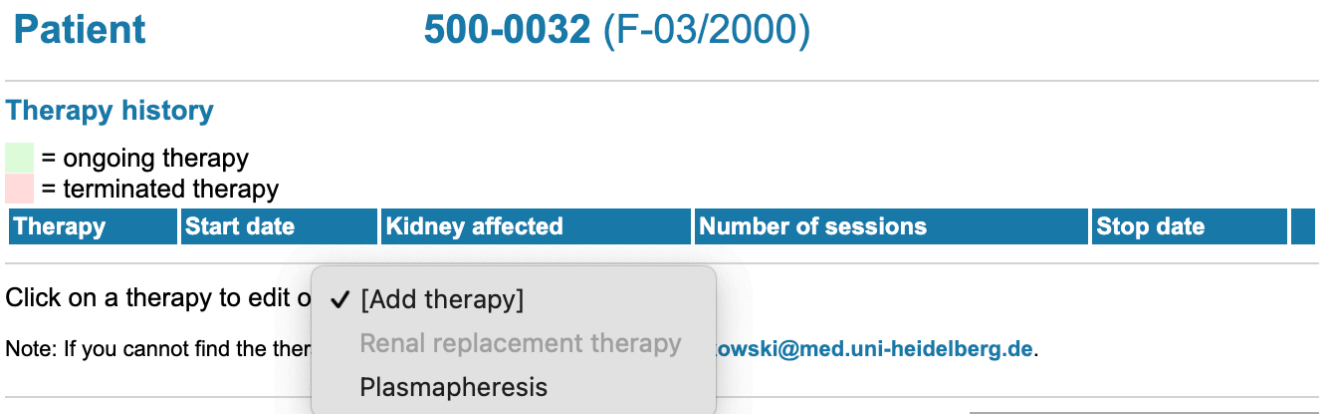

Figure 10: Extracorporal therapies for patients enrolled in the IgAN / IgAV subregistry.

MEDICATIONS

Under the medications module, specific medications usage information is collected (Figure 11).
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 calculte the dosae/kg/day field displayed in the table in Figure 11).
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.

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

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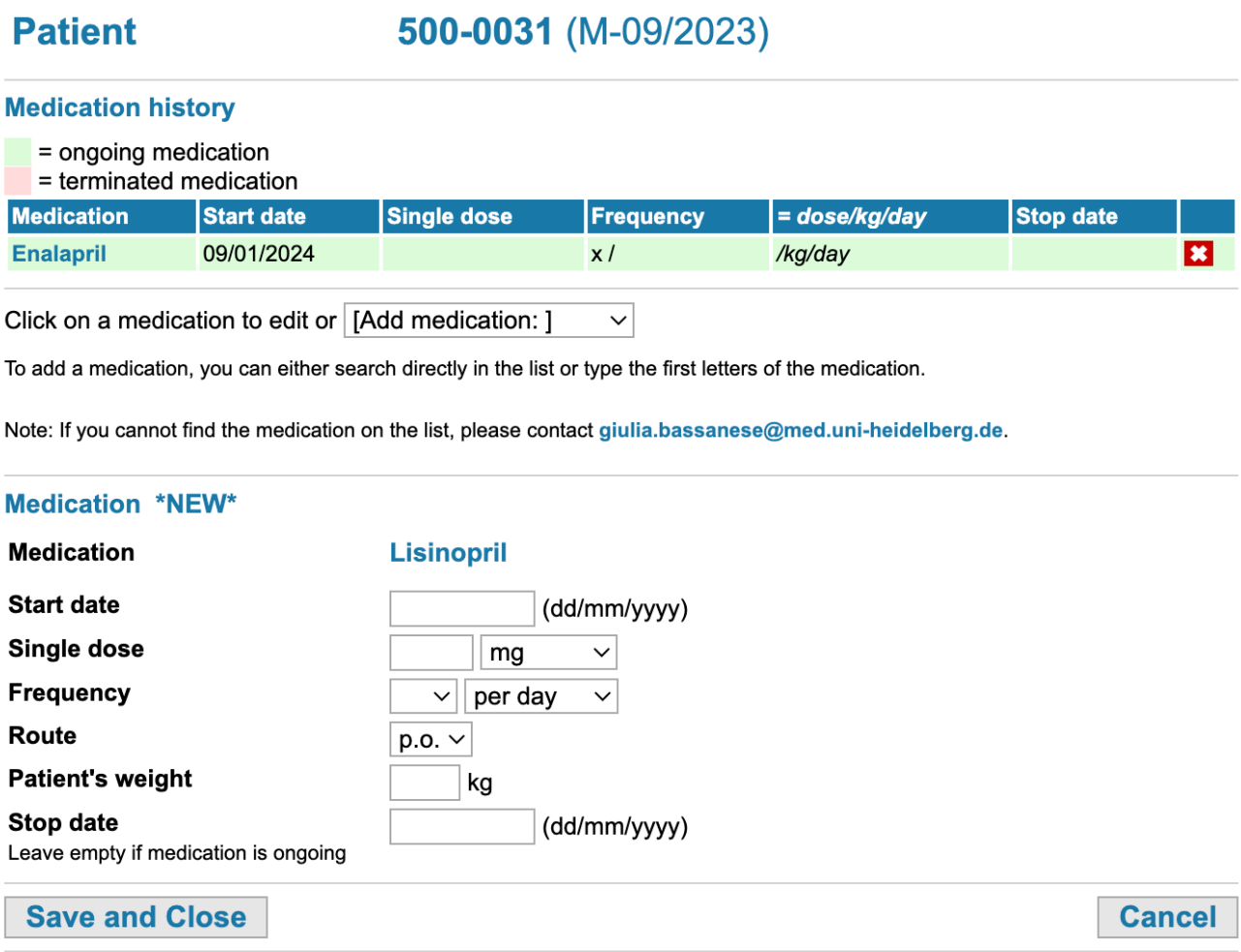

Figure 11: Medication module for patients enrolled in the subregistry.

CONTACT:

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