

**Patient**

Surname:

First name:

Date of birth (dd-mm-yyyy):

Gender: male female

Country:

Sample ID:

University Medical Centre Utrecht
 Dept. Of Clinical Chemistry and Haematology
 Centrale Balie
 Room G03.330
 Heidelberglaan 100
 3584 CX Utrecht
 The Netherlands
 Tel.: +31 88 75 58826

Pyruvate kinase deficiency diagnosis

(test costs sponsored by Agios Pharmaceuticals)

Requested by*

Organization		Contact information Name: Telephone: E-mail:
Department		
Address		
Collection date		
UMCU organization code <i>(to be filled in by the receiving lab)</i>		

*Agios Pharmaceuticals will be informed on contact details of the requesting physician and will receive de-identified patient information.

Material: Blood sample provided with the patient's name and date of birth.

Transport: Samples should be shipped at 4°C (not frozen!) by courier service. Samples can be delivered from Monday until Thursday. On Thursday samples should be delivered before 12AM.

Form: Please fill out one form per patient.

Enzyme disorders (2x 6 mL EDTA)A

Agios

The analysis consists of pyruvate kinase enzymatic assay or, if applicable, additional biochemical testing and/or DNA sequence analysis of PKLR.

Informatie voor medewerkers van de Centrale Balie, LKCH, UMC Utrecht:

- Schrijf de patiënt in HiX in op de reguliere wijze
- Meld de order aan in GLIMS via het formulier UMC-RodeBloedcel, tab Her.Hem.Anemie
- Vink '**Agios**' aan (er worden automatisch bepalingen toegevoegd)
- Rond de aanmelding in GLIMS af en verwerk het materiaal op de reguliere wijze
- Deze order hoeft niet met PAG module ingeschreven te worden

Please also complete the back of this form!



Supplemental information for pyruvate kinase deficiency diagnosis

Patient

Surname:

First name:

Date of birth (dd-mm-yyyy):

Family history

Ethnic background

Table with 3 columns: Condition, No, Yes. Rows include Consanguinity, Hematological disorder, Splenomegaly/splenectomy, Gallstones/cholecystectomy.

Patient history

Table with 3 columns: Condition, No, Yes. Rows include Neonatal jaundice, Exchange transfusion, Splenomegaly/splenectomy, Gallstones/cholecystectomy, Transfusions (with Number and Date last transfusion), Hemoglobinuria, Aplastic crises, Non-hematological symptoms.

Clinical information

Table with 3 columns: Condition, No, Yes. Rows include Icterus, Splenomegaly, Hepatomegaly, Non-hematological symptoms.

Representative lab results (please include units)

Table with 4 columns: Lab test, blank, Lab test, blank. Rows include Hb, Ht, RBC, MCV, MCH, MCHC, RDW, WBC, PLT, Reticulocytes, Red blood cell morphology, Bilirubin (conjugated/unconjugated), Haptoglobin, Lactate dehydrogenase, Ferritin, Osmotic fragility (please indicate used test), Hemoglobinopathy, Direct Coombs test, CD55/CD59.

Other information

Four horizontal lines for additional information.



Optional Use of Information for Future Contact by Agios

The company paying for PK deficiency testing of your patients, Agios Pharmaceuticals, Inc. ("Agios"), would like to obtain your name, institutional affiliation, phone number and email (your "Contact Information") from UMC Utrecht for the purpose of (i) contacting you regarding upcoming clinical trials of Agios investigational products, and (ii) providing you with general information about PK deficiency (collectively, the "Purpose"). Importantly, you are not required to consent to the sharing of your Contact Information with Agios in order for your patients to receive testing paid for by Agios.

By signing below, you:

Consent to Agios obtaining your Contact Information from UMC Utrecht and processing your Contact Information for the Purpose

Consent to UMC Utrecht transferring your Contact Information to the United States and potentially other third countries for use by Agios for the Purpose

Understand that you have the right to withdraw your consent at any time by contacting Agios at (617) 649-8600, but doing so does not affect the lawfulness of the processing of your Contact Information that took place prior to your withdrawal of consent.

Name:

Date:

Signature: