



Eur-USH: European Research Projects on Rare Diseases driven by Young Investigators

Username *
Password *
Default username test/test or admin/admin

Please click here if you have forgotten your password

☐ Remember me next time

Login

No button to click

To the centre

ERA-Net for Research Programmes on Rare Diseases

Principal investigators: Kerstin Nagel-Wolfrum, PhD, Johannes Gutenberg University of Mainz , Institute of Zoology, Dept. Cell and Matrix Biology, Mainz, Germany (Coordination); Leal Sérgio Casimiro da Silva, AIBILI, 4C – Coimbra Coordinating Centre for Clinical Research, Coimbra, Portugal; Eduardo José Gil Duarte Silva, MD PhD, IBILI- Faculty of Medicine – University of Coimbra, Center for Hereditary Diseases and Visual Neurosciences Laboratory, Coimbra, Portugal; Ieva Sliesoraityte, MD PhD, INSERM CIC 503 Hôpital des 15/20, Institut de la Vision, Paris, France; Christel Vaché, PhD, Montpellier, France; CHU, Laboratoire de génétique moléculaire, INSERM, Montpellier, France; Erwin van Wijk, PhD, Radboud University Nijmegen Medical Centre, Dept. Otorhinolaryngology, Nijmegen, The Netherlands

Text OK but in very small letters

Principal investigators: Kerstin Nagel-Wolfrum, PhD, Johannes Gutenberg University of Mainz , Institute of Zoology, Dept. Cell and Matrix Biology, Mainz, Germany (Coordination); Leal Sérgio Casimiro da Silva, AIBILI, 4C – Coimbra Coordinating Centre for Clinical Research, Coimbra, Portugal; Eduardo José Gil Duarte Silva, MD PhD, IBILI- Faculty of Medicine – University of Coimbra, Center for Hereditary Diseases and Visual Neurosciences Laboratory, Coimbra, Portugal; Ieva Sliesoraityte, MD PhD, INSERM CIC 503 Hôpital des 15/20, Institut de la Vision, Paris, France; Christel Vaché, PhD, Montpellier, France; CHU, Laboratoire de génétique moléculaire, INSERM, Montpellier, France; Erwin van Wijk, PhD, Radboud University Nijmegen Medical Centre, Dept. Otorhinolaryngology, Nijmegen, The Netherlands

Patients

Displaying 1-5 of 5 results.

Operations
Search Patients

ID: [13](#)
Systemid: PATIENT5228c3f316a48
Gender: M
Date of birth: 02-09-2013
Informed consent:
Confirmed mutation: YES

ID: [14](#)
Systemid: PATIENT5228c76c7baaf8
Gender:
Date of birth: 01-01-1970
Informed consent:
Confirmed mutation:

ID: [15](#)
Systemid: PATIENT522a5a7233af5
Gender: M
Date of birth: 11-06-2012
Informed consent:
Confirmed mutation:

ID: [16](#)
Systemid: PATIENT522c9ee973bea
Gender:
Date of birth: 01-01-1970
Informed consent:
Confirmed mutation:

ID: [17](#)
Systemid: PATIENT522cc90db9569
Gender:
Date of birth: 01-01-1970
Informed consent:
Confirmed mutation:

List Patients

Search Patients

Manage Patients (*better word
manage instead update, should
hold same function*)

Not corrected
number 5

ID: [13](#)
Systemid: PATIENT5228c3f316a48
Gender: M
Place of birth: PIETA'
Date of birth: 02-09-2013
Informed consent:
Confirmed mutation: YES

ID: [14](#)
Systemid: PATIENT5228c76c7baaf8
Gender:
Date of birth: 01-01-1970
Informed consent:
Confirmed mutation:

ID: [15](#)
Systemid: PATIENT52298c3045f0e

4. Exclude, not relevant info

5. Include after confirmed mutation
2 more fields: "File complete": YES
or NO options (appears YES, if all
fields entered but for some reasons
not submitted) and "File
submitted" ": YES or NO options
(appears YES, if submitted). NOTE:
edition or deletion of submitted files
only possible by contacting admin

For both last only YES
or NO options for both

Pls correct search window !!!! Everybody will be in schock when see so difficult search – answer will be imposible to use DB, as too difficult ☹

4 page

1. Change all table to this one



2. Change to only 3 operations as in page 3

4 page

1. Change all table to this one

2. Change to only 3 operations as in page 3

3. Exclude 3 buttons

4. Include 4 buttons: "Mutation confirmed", "Centre", "Responsible physician", "Data submitted" after Date

5. Exclude those empty windows

6. One all data uploaded to the DB, and submit button clicked, no edition possible, and edition button should change to some other sign, delete button should not be active as well.

Search Patients

Search criteria (than appears table bellow, it is enough for search 6 bellow criteria)

ID
Centre
Responsible Physician
Gender
Date of birth
Diagnosis

Operations

- List All Patients
- Search Patients
- Delete Patient
- Update Center Specific Data
- Update General Patient Data
- Update Genetic Data
- Update Ophthalmologic Data

List All Patients
Search Patients
Update Patients

Displaying 1-3 of 3 results

ID	Systemid	Gender	Place of birth	Date of birth	Interpased consent
13	PATIENT5228c3f318a48	M	PIETA	02-09-2013	
14	PATIENT5228c76c7baf8			01-01-1970	
15	PATIENT52289c3048e9c			01-01-1970	



Patient Management Create new patient Create new family Logout (admin)

Home » Patients » 13 » 13

Update General Patient Data

Fields with * are required.

Center A (created patient) *

University Of Malta
(Select a center)
University Of Malta
Mater Dei

Center C
(Select a center)

Responsible Physician Center A *

Dr Alban2 test

Responsible Physician Center B

Responsible Physician Center C

Submit

Internal Id of Center A

Internal Id of Center B

Internal Id of Center C

Operations

List All Patients

Search Patients

Delete Patient

Update Center Specific Data

Update General Patient Data

Update Genetics

Update Ophthalmologic Data

Only centres to select or free text to enter

Center A (created patient) *

University Of Malta

(Select a center)

Center B

(Select a center)

Center C

(Select a center)

Responsible Physician Center A

Dr Alban2 test

Responsible Physician Center B

Responsible Physician Center C

Submit

Internal Id of Center A

1. Here should be selection function for all same and other, than should be entered by hand

Johannes Gutenberg University of Mainz
Coimbra Coordinating Centre for Clinical Research
University of Coimbra, Center for Hereditary Diseases and Visual Neurosciences Laboratory
Institut de la Vision, Rare disease reference centre, INSERM
Laboratoire de génétique moléculaire, INSERM
Radboud University Nijmegen Medical Centre

[Patient Management](#) [Create new patient](#) [Create new family](#) [Logout \(admin\)](#)

[Home](#) > [Patients](#) > [17](#) > Update Genetic Data

Update Patient Genetic Data 17

Create new genetic data

*Fields with * are required.*

Mode of inheritance *

not applicable

Allele status *

not applicable

Dna source *

not applicable

Screened for mutations

not applicable

Date of screening

Level of certainty

not applicable

Create

Responsible Mutations

Add a new mutation

*Fields with * are required.*

Patient locus *

(Select a locus)

First allele *

Not applicable

First allele mutation

Second allele *

Not applicable

Second allele mutation

Third allele

Not applicable

Third allele mutation


Fourth allele

Not applicable

DNA (all capitals)

Create

→ change to SAVE everywhere !!!



[Patient Management](#) [Create new patient](#) [Create new family](#) [Logout \(admin\)](#)

[Home](#) » [Families](#) » 2

View Family #2

ID	2
Systemid	1
Comment	Test Family 1 e


Patients in Family

ID	13
Systemid	PATIENT5228c3f316a48
Gender	M
Remove Patient	Remove Patient
ID	14
Systemid	PATIENT5228c76c7baf8
Gender	Not set
Remove Patient	Remove Patient

Operations

[List Family](#)
[Create Family](#)
[Update Family](#)
[Delete Family](#)
[Manage Family](#)
[Add patient](#)

Should be everything in manage (do not doubled information) ;
As simple as possible !!!



[Patient Management](#) [Create new patient](#) [Create new family](#) [Logout \(admin\)](#)

[Home](#) » [Families](#) » Create

Create Family

Fields with * are required.

Systemid *

Comment

Create

Operations

[List Family](#)
[Manage](#)

Should be scroll option to select system ID
Comments without *

Ophthalmology

Download function is, works but cannot see image but only script. Required function to see images! Try to work on it when you will be done with corrections in ophthalmology part, because I need print screens for presentation as well.

Ophthalmological Color Vision tests

left

Fields with * are required.

Performed *
yes

Type
D15

D15 Desaturated Order
12

D15 Saturated Order

Lea Result

Hue28 performed

Save

right

Fields with * are required.

Performed *
yes

Type
D15

D15 Desaturated Order
55

D15 Saturated Order

Lea Result
22

Hue28 performed

~~Save~~

Try to put as a table for one exam, as send previously , because it is faster to enter.

Only one save button for one test. Needed to save time to put data!!!