

# Fibrous Dysplasia/McCune Albright Syndrome module

*Meeting 11-09-2023*



**EuRRECa**

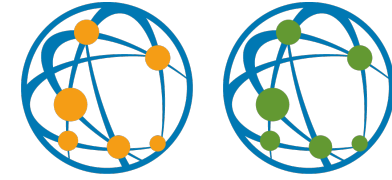
European Registries for  
Rare Endocrine Conditions



**EuRR-Bone**

European Registries for Rare  
Bone and Mineral Conditions

# Evolving of the Registries in time



Patients and carers



E-reporting -  
Rare Conditions  
tool (e-REC)

Core  
Registry



Calcium &  
Phosphate

Bone

Moving  
servers  
LUMC

Condition  
- Specific  
Modules



Integration of the  
Registries in WP 5 of the  
European Reference  
Networks

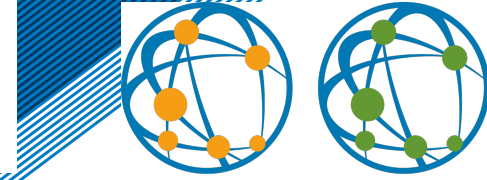
2017

2018

2020

2022

2023



## EuRR-Bone

European Registries for Rare  
Bone and Mineral Conditions

### FIBROUS DYSPLASIA/MCCUNE ALBRIGHT SYNDROME MODULE

The disease specific module was launched April 2022 and is the work of the vertical theme **Fibrous Dysplasia/McCune Albright Syndrome (FDMAS)**

Want to start using the module? Get access to the Core registry [here](#). After entering the patient in the Core Registry, the FDMAS module appears automatically and is ready to use.

If you have questions or interest in joining the working group, please contact us on [EuRR\\_Bone@lumc.nl](mailto:EuRR_Bone@lumc.nl)

The full data dictionary can be downloaded here when available.

The modules should be updated every 12 months in adults and every 6 months in children when patients are under active control. If not updates should be provided every 3 years. Of course additional data can be entered on demand.

You only have to fill out the relevant modules to your patient eg when no Cranial Facial Fibrous Dysplasia or Endocrinopathies are present, the modules can be left empty.

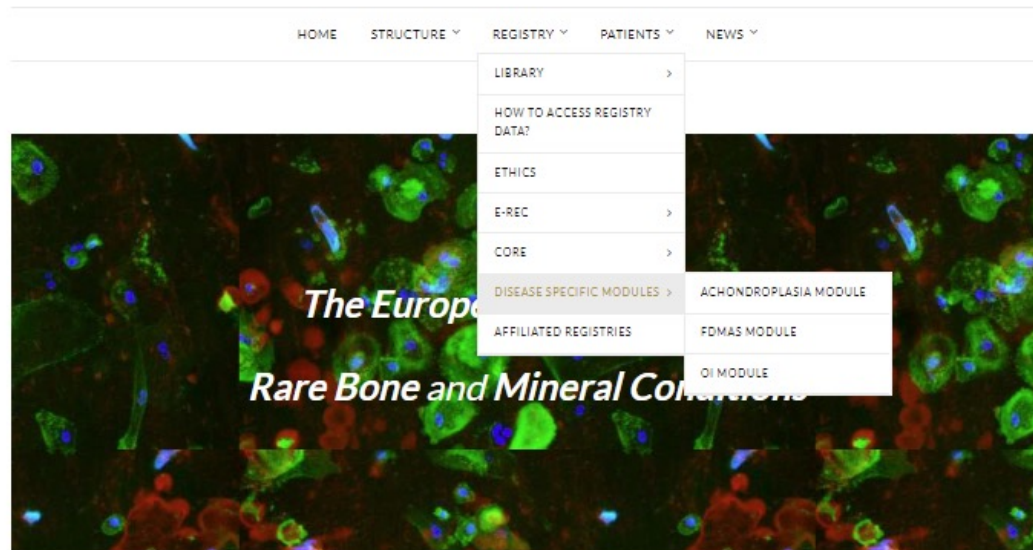
**Do not forget** for all bone conditions EQ5D and mobility should be assessed (either by clinician or patient with access) yearly. You will need to set those within the general bone dysplasia module

Tools used in the module :

[Brief Pain Inventory](#) (coming soon in 10 languages) in adults and children

[EQ5D](#)

Calculation of the TmP/GFR for the assessment of hypophosphatemia

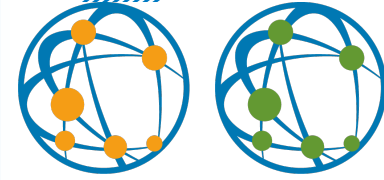


## What is EuRR-Bone?

Expert centers for rare bone and mineral conditions and patient representatives have joined their forces and started the European Registries for Rare Bone and Mineral Conditions (EuRR-Bone) in April 2020. This project works closely with the European Registries for Rare Endocrine Conditions project (EURRECa) and the European Reference Networks for Rare Bone and Rare Endocrine conditions and includes:

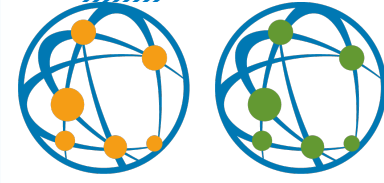


# FD/MAS module



Questionnaire: Fibrous dysplasia/McCune Albright module

Anthropometry	Basic disease module	Disease characteristics	McCune-Albright syndrome	Craniofacial FD	Therapy
Assessment Date			?	<input type="text" value="mm/dd/yyyy"/>	
Height (cm)			?	<input type="text"/>	
Height SDS			?	<input type="text"/>	
Weight (kg)			?	<input type="text"/>	
Weight SDS			?	<input type="text"/>	
BMI			?	<input type="text"/>	
BMI SDS			?	<input type="text"/>	



Questionnaire: Fibrous dysplasia/McCune Albright module

Anthropometry

Basic disease module

Disease characteristics

McCune-Albright syndrome

Craniofacial FD

Therapy

Assessment Date



mm/dd/yyyy



Age at Assessment Date



## Endocrinopathies

Endocrinopathy



- Select -

## Musculoskeletal

Fractures due to fibrous dysplasia

- Select -



Limb deformity due to fibrous dysplasia

- Select -



Scoliosis due to fibrous dysplasia



Progressive scoliosis: scoliosis that worsens by more than 5 degrees or more between x-rays



Pain at fibrous dysplasia site

- Select -



## Bone and mineral metabolism

Alkaline phosphatase

- Select -



CtX-1

- Select -

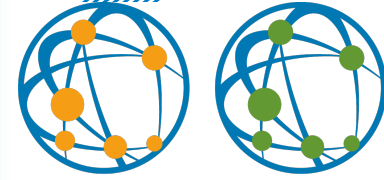


Hypophosphatemia, serum confirmation










- Select -



# FD/MAS module



Questionnaire: Fibrous dysplasia/McCune Albright module

Anthropometry	Basic disease module	Disease characteristics	McCune-Albright syndrome	Craniofacial FD	Therapy
Assessment Date				<input type="text" value="mm/dd/yyyy"/>	
Age at Assessment Date				<input type="text" value="Age at Assessment Date for this Section"/>	
Endocrinopathy				<input type="checkbox"/> None <input type="checkbox"/> Neonatal hypercortisolism <input type="checkbox"/> Precocious puberty <input type="checkbox"/> Thyroid involvement <input type="checkbox"/> Growth hormone excess <input type="checkbox"/> Hyperprolactinemia	
Age at presentation of neonatal hypercortisolism if applicable				<input type="text"/>	
Age at presentation of precocious puberty if applicable				<input type="text"/>	
Age at presentation of hyperthyroidism if applicable				<input type="text"/>	
Age at presentation of GH excess if applicable				<input type="text"/>	
Age at presentation of hyperprolactinemia if applicable				<input type="text"/>	



# FD/MAS module



Questionnaire: Fibrous dysplasia/McCune Albright module

Anthropometry

Basic disease module

Disease characteristics

McCune-Albright syndrome

Craniofacial FD

Therapy

## Past Therapy

Assessment Date



mm/dd/yyyy



Age at Assessment Date



FD related medication

- None
- Active vitamine D
- Bisphosphonates oral
- Bisphosphonates intravenous
- Cholecalciferol
- Denosumab
- Phosphate
- Not known
- Other

Other



Indication for FD related medication

- Growth
- Low phosphate
- Pain
- Prophylaxis
- To improve quality of life
- Not known

## Current therapy

Assessment Date



mm/dd/yyyy

Age at Assessment Date



FD related medication

- None
- Active vitamine D
- Bisphosphonates oral
- Bisphosphonates intravenous
- Cholecalciferol
- Denosumab
- Phosphate
- Not known
- Other

Other

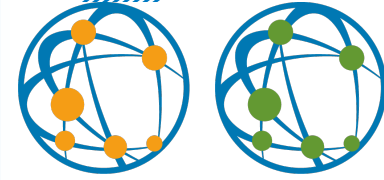


Indication for FD related medication

- Growth
- Low phosphate
- Pain
- Prophylaxis
- To improve quality of life
- Not known



# FD/MAS module



Questionnaire: Fibrous dysplasia/McCune Albright Condition specific patient reported outcomes

Professionals I/the patient see

Assessment Date ?

Age at Assessment Date ?

How many health professionals do you/the patient see?

1  
 2  
 3  
 4  
 5

Which health professionals do you/the patient see regularly? ? Professionals that take part in your follow up, therefore, you have appointments at regular intervals. (NT)

Opththalmologist  
 Oral maxillary surgeon  
 Ortopaedic surgeon  
 Pediatrician  
 Physiotherapist  
 Rehabilitation doctor  
 Rheumatologist  
 Other

Other (freetext) ?