



European
Reference
Network

MetabERN

European Reference Network
for Hereditary Metabolic Disorders

MetabERN Annual Meeting

The Work done in Work Package 7



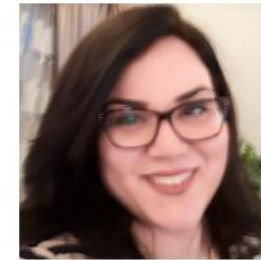
9-10 April 2018,
Lindner Hotel, Frankfurt (Germany)

WP-7 Team

- Nadia Belmatoug : Referral Center for Lysosomal Diseases (APHP)
- Azza Khemiri : G2M French network
- Margaret Giuliani : Patient association : Vaincre les Maladies Lysosomales
- Abel Poucet webmaster



DR NADIA BELMATOUG
Leader of Workpackage 7 :
"Education training and
capacity building" and
Coordinator of French
Reference Centre of Lysosomal
disease - Assistance Publique
- Hôpitaux de Paris (APHP) -
Beaujon Hospital.



**AZZA BEN HAMIDA-
KHEMIRI**
Project leader of the French
Network "Filière G2M
(Groupement des Maladies
Métaboliques)" of rare
metabolic diseases in charge of
MetabERN, Europe and
International and research.



MARGARET GIULIANI
Member of French association
of patients VML "Vaincre les
Maladies Lysosomales" and
EGA "European
GaucherAlliance". She is the link
between E-PAG, EURORDIS
and WP7. In charge of revision
of education section of the
website for English language.



ABEL POU CET
Webmaster of the
website "MetabERN:
Education, training and
Capacity building".

- Dominique Roland, Manuel Schiff, Pascale de Lonlay : HCPs

- Lut De Baere : Metabolic diseases association of patients in Belgium « BOKS », Eurordis,

- Anne Sophie Lapointe : VML, Eurordis

- Anne Hugon : Association Française des Glycogénoses



Subnetwork	Leader	Members	Country
Subnetwork 1: AOA	Dries Dobblaere	Anibh Martin Das	
		Dobbelaere Dries	France
		Debray Francois-Guillaume	Belgium
		Javier de las Heras	
		Francois Eyskens	Belgium
Subnetwork 2: C-FAO		Anne Hugon	France
Subnetwork 3: LSD	Dominique Roland	Serena Gasperini	Italy
		Luísa Maria de Abreu Freire Diogo Matos	Portugal
		Ana Maria Simões Mendes Gaspar, Patricio Aguiar	Portugal
		Patrick Deegan	United Kindom
Subnetwork 4: PD		Eyskens François	Belgium
		Renza Gallupi Barbon	
Subnetwork 5: PM-MD		Manuel Schiff	France
Subnetwork 6: CDG	Pascale De Lonlay	Nathalie Seta	France
		Arnaud Bruneel	France
Subnetwork 7: NOMS		Julia Hennermann	Deutschland
Patients Organizations	AOA sub-group	De Baere Lut	
	C-FAO sub-group	Anne Hugon	France
	LSD sub-group	Anne-Sophie Lapointe or Christine Lavery	France
	PD sub-group	Barbon Renza	
	PM-MD sub-group	Arbellino Cinzia	
	CDG sub-group	Ferreira Vanessa	
	NOMS sub-group	Sproedt Claudia	

WP7: Education-Training-Capacity-building & Training

OBJECTIVE:

- Identification of **already available training and teaching programmes and capacities** in the network.
- Identification of **already available materials about training and teaching programmes** and capacities in the network.
- Identification of training, teaching, capacities **needs, priorities** within the network.

WP7: Education-Training-Capacity-building & Training

OBJECTIVE:

- Develop comprehensive programmes for the benefit of **different target groups**
 - Participating HCPs
 - Young students (medical students, PhD),
 - Nurses, Paramedics
 - Researchers, Biologists ...
 - Patients and their families, caregivers,
- One particular focus will be put on capacity-building in **affiliated members** as well as those **centres currently with less resources in certain areas**.

WP-7 : Objectives

OBJECTIVE:

- To contribute to the development of educational tools
- To develop academic training standards for European medical students and fellows
- To develop a credit system for acknowledgement of existing courses
- To develop eLearning modules
- Dissemination of highly specialized knowledge and expertise within the members of the ERN
- Case-oriented teaching

METHODS:

- During the first year, WP7 focused on the **identification of teaching and training programmes already available to HCPs and patient organisations within the network.**
- **An overview of available programmes is and will be disseminated** through the website as well as through regular updates on upcoming programmes throughout the year.

[website : metabern-educ.eu](http://metabern-educ.eu)

How we work : Material collection with WP 7 leaders

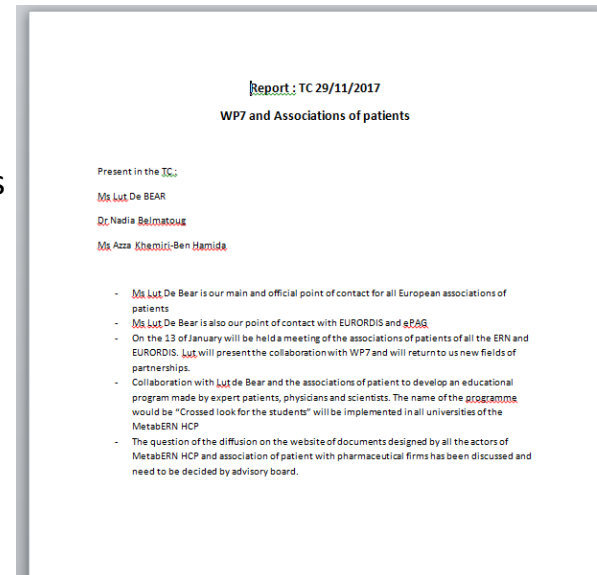
- Contact with MetabERN project Manager (Cinzia Belletato) and leaders of subnetworks by WP7 team to ask for documents already supplied for the MetabERN application and to identify existing and available teaching, training programs and resources within the network.
- Contact with Lut De Beare and patient associations to collect documentation
- To hold the schedule of meetings, conferences, congresses... up to date
- *Contact with Recordati foundation for transmission of courses*
- *Discussion about setting up of a European therapeutic education school with Vitaflo*

Methodology: task list approach



Teleconference .

- Put a link on the portal MetabERN for the site MetabERN education
- Set up a questionnaire to collect documents on behalf of all the HCP
- Collection of documents on behalf of the HCP
- Translation of documents
- Collaboration with the SSIEM: interlocutor: Mr. Andrew Morris
- The possibility of the development of partnership with private companies in the domains of e-learning, the design of applications ...)
- Possibility of financing by MetabERN
- The question of diffusion on the website of documents designed by all actors of MetabERN, HCP and association of patients with pharmaceutical firms
- Creation and organization of events the site MetabERN education: courses, tutorial, conference
- Live broadcasts which we could use on the site: channel on youtube or other means
- Capacity building: implementation of European Diploma, collaboration with the European Commission



WP 7- Education in Year-1

Deliverables achieved:

- **WP7 Organizations:** Identification of 1 Leader and 5 members for WP7 per subnetwork, the list has to be reviewed regularly
- **Design and elaboration of a «subwebsite»** template containing MetabERN library for education and training incorporated in the MetabERN portal
- Contact with webmaster and discussion about how to implement this «subwebsite.
- Contact with WP2
- Contact with learned societies and websites concerned by metabolic rare diseases to make a link with «the website» to increase visibility
- Proposition of an on line mock-up of «subwebsite»
- Margaret Giuliani: Member of French association of patients VML “Vaincre les Maladies Lysosomales” and EGA ‘European Gaucher Alliance’. She is the link between E-PAG, EURORDIS and WP7. In charge of revision of education section of the website for English language.

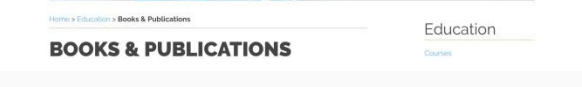
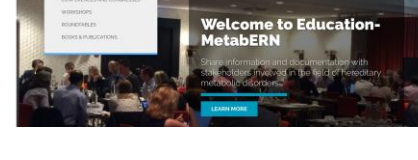
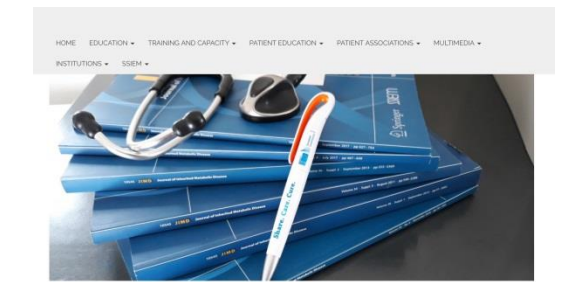
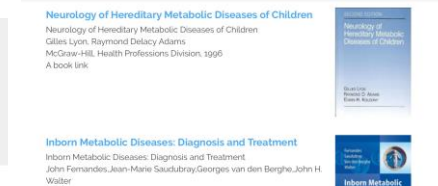
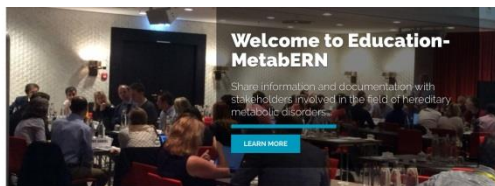
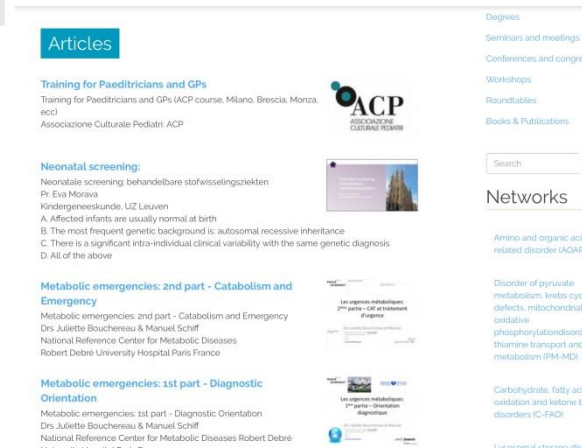


Deliverable, Website : Metabern-educ.eu

- Dedicated website : unique in the ERNs

- Collect :

- List of available courses
- Catalogue of educational material, patient Information materials
- Educational activities and tools already available
- Academic initiatives in HCP, programmes developed by scientific societies



Deliverable, documents on the website : Metabern-educ.eu

For patients

Educational Therapeutic Programmes : 12

Training, information and publication : 3

Videos : 3

For professionals

Courses : 6

Degrees : 2

Seminar and meetings : 2

Conferences and congresses : 8

Workshop: 1

Roundtable : 1

Books and publications : 23

Training sessions : 1

Webinar : 1

Videos : 1

For both patients and professionals

Apps : 16

Videos : 7

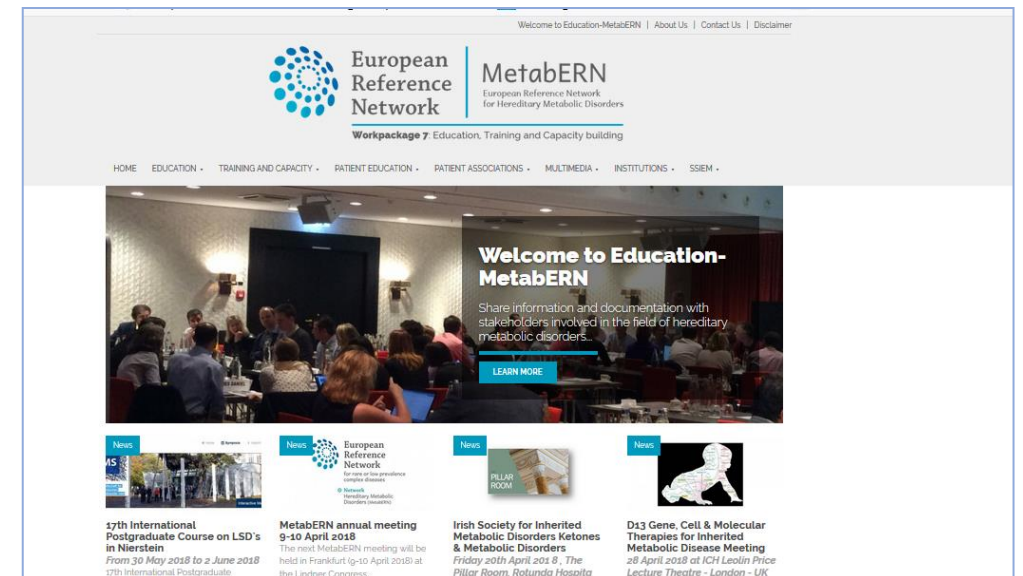
Articles dedicated to medical societies 17

Articles dedicated to hospitals and reference centres : 23

Articles related to regulatory agencies : 4

SSIEM : 2

Links : a lot



The screenshot shows the homepage of the MetabERN website. At the top, there is a navigation bar with links for 'Welcome to Education-MetabERN', 'About Us', 'Contact Us', and 'Disclaimer'. The main header features the 'European Reference Network' logo on the left and the 'MetabERN' logo on the right, with the tagline 'European Reference Network for Hereditary Metabolic Disorders'. Below the logos, it states 'Workpackage 7: Education, Training and Capacity building'. A secondary navigation bar includes links for 'HOME', 'EDUCATION', 'TRAINING AND CAPACITY', 'PATIENT EDUCATION', 'PATIENT ASSOCIATIONS', 'MULTIMEDIA', 'INSTITUTIONS', and 'SSIEM'. The main content area features a large banner image of a meeting with the text 'Welcome to Education-MetabERN' and 'Share information and documentation with stakeholders involved in the field of hereditary metabolic disorders...'. Below the banner, there are four news items, each with a small image and a title: '17th International Postgraduate Course on LSD's in Nierstein', 'MetabERN annual meeting 9-10 April 2018', 'Irish Society for Inherited Metabolic Disorders Ketones & Metabolic Disorders', and 'D13 Gene, Cell & Molecular Therapies for Inherited Metabolic Disease Meeting'.

First results for documentation on training list of available courses

- France 5
- Germany : 1
- Spain : 1
- Netherlands : 1 for the Lysosomal group
- Italy : 2
- Zagreb : 1
- Belgium : 3

Results of Survey on training and education

9 April MetabERN meeting

- Assessment of educational and training needs in MetabERN
- Establish priorities

- **First result** : A kind of basic training with very simple explanation in order to know how metabolic system should work, so as to better understand the errors...(association of patient)

MetabERN Work package 7: Education, training and capacity building



Work package 7: Survey on training and internship

Answer with X

A/Training

1/ Do you have any training

Hereditary metabolic disorder

Yes

No

2/ Intended for which stakeholder

Medical students:

Physicians:

MetabERN Work package 7: Education, training and capacity building

Precise the characteristics of training: (University diploma, master, PhD...)

Precise the details about this training

Website:

Contact:

Mail:

B/ Internship

Do you have an internship in the field

Yes

No

Name of internship:

Characteristics:

MetabERN Work package 7: Education, training and capacity building

1/

2/

3/

Training will be organized by e-learning?

Yes

No

Comments:

Training will be organized in your HCP or University?

Yes

No

Comments:



Capacity building : Name of the programme

“Regards croisés” : “Fresh perspective” programme

«Around patients stories” : A multidisciplinary approach

- Project of programme dedicated to description of patient pathway; by patients, doctors, nurses and expert patients

- Teleconference on 4 April 2018 with associations of patients:
to have their opinion about this programme

Survey on : Mutidisciplinary approach around patients stories

MetabERN-WP7: Education, training and capacity building
Training programme: "Multidisciplinary approach around patients stories"

⊕ TITRE DE LA PAGE

1. This training seems to you interesting?

Yes
 No

Comment

2. Is It feasible in your HCP/University?

Yes
 No
 Comment

3. In your opinion, what is the main target of this training ?

Medical students
 Nurses
 Patient associations
 General practitioner
 All

3. In your opinion, what is the main target of this training ?

Medical students
 Nurses
 Patient associations
 General practitioner
 All

Comment

⊕ NOUVELLE QUESTION ▼

ou copiez et collez vos questions

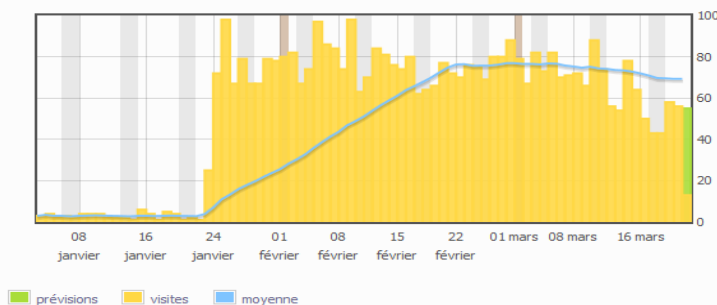
Terminé



Evaluation of the website visit

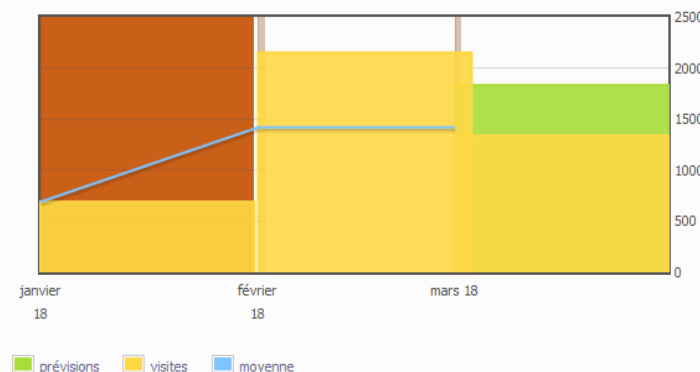
- 1st step: Requiring the opinion of the advisory board members,
2nd step: of all HCP members via sub-groups leaders with a short questionnaire
- Requiring the opinion of patient associations with a short questionnaire
- Website : follow-up of visits

follow-up of daily visit



Résumé	
Maximum	98
Moyenne	69
Aujourd'hui	13
Hier	56
Total	4177
Popularité du site	113

follow-up of monthly visit



follow-up of monthly visit

Date	prévisions	visites	moyenne
janvier 2018		689	689
février 2018		2149	1419
mars 2018	1832	1339	1419

WP 7- Education in Year-2

Deliverables to be achieved:

- Consolidate and reinforce its structure and mode of operation
- Improving awareness for the disease among caregivers (General Practitioners (GPs), school doctors, general public)
- Increase knowledge available online (website, youtube)
- Website evaluation
- **Collaboration with SSIEM**

Because of large amount of work that has been done on the setting up of the website the report has been delayed. There is however a good overview of which training programmes are available and cooperation with SSIEM has started. The report will be finalised in April 2018. This delay will not have a negative influence on the attainment of the deliverables for Y-2.



Collaboration with others ERNs on transversal topics, EJP Do we have to develop these transversal topics in MetabERN ?

Training on

- Techniques, diagnostic tool,
- Quantitative outcome, Patient Report outcome
- Clinical trials

Medical Genetics : genomic NGS

Rare Diseases Orphan Drug

Rare Diseases Orphan Registries

CPMS : Webinars

Encountered problems/Questions

- Promote education and training in others learned societies paediatrics, haematology etc
- **Training school for early stage researchers to present their work to patients and families**
- **Partnership with industry, private company, programmes developed with the institutional partnership with pharmaceutical company**



Interaction with the Subnetworks: What has worked well and what could be improved ?

- Close collaboration with WP7 leaders
- Improve collaboration with all Subnetwork Leaders



European
Reference
Networks

Patient Involvement in WP-7

- Good interaction and Collaboration with patients associations
- Some are reluctant to give materials
- Problems of languages and translation
- Avoid redundancy with the work of the associations and Eurordis

