



European
Reference
Network

MetabERN

European Reference Network
for Hereditary Metabolic Disorders

Workpackage 7: Education, Training and Capacity building

MetabERN Annual Meeting

Work progress of Workpackage 2 and 7

4-6 April 2019

Frankfurt, Germany



WP7

Participants: 15

- HCP : 6
- Patient Organisation : 2
- Biologist : 1
- Project leader 2
- Others : 4

Simon Bond



WP 7

Nadia Belmatoug, Partners

Subnetwork 1: AOA	Dries Dobbelaere
Subnetwork 2: C-FAO	Philippe Labrune
Subnetwork 3: LSD	Dominique Roland
Subnetwork 4: PD	Eyskens François
Subnetwork 5: PM-MD	Manuel Schiff
Subnetwork 6: CDG	Pascale De Lonlay Arnaud Bruneel
Subnetwork 7: NOMS	Julia Hennermann
Patient Organisation	Margaret Giuliani

The actions of WP 7

Creation of WP7 « Sub » Website

www.metabern-edu.eu



European
Reference
Network

MetabERN
European Reference Network
for Hereditary Metabolic Disorders

Workpackage 7: Education, Training and Capacity building

MetabERN : Hosting of the website



Help from the French rare metabolic diseases network

- Design and webmaster :
- Project Officer : Azza Khemiri : “European mission”
- Grant : 6000 Euros, maintenance



Objective of the “sub”website

- **The diffusion of** news, programs, training, courses, degrees resources, (institutions and PO) etc.
- **FOR patients and caregivers** and **health professionals and students**
- **BY patient organizations** and **health professionals**



Actions of Workpackage 7

Goal : Mapping of current teaching and learning programmes

Action and Tools : Short questionnaire about priorities on training and education in HCPs of MetaERN

Results : http://www.metabern-educ.eu/IMG/pdf/word_questionnaire041018-2.pdf



WP7: Education, training, and capacity building

Questionnaire about training and education in HCPs of MetaERN

1

The actions of Workpackage 7

Website



Working method

- Members dedicated to WP7 in each SBN provide us documents, courses etc.
- Azza and Nadia : “permanent” watch on internet, youtube, online publications, google scholar for books etc.
- Policy about materials done with an industrial partnership ?
- Validation of the documents

metabern-educ.eu



EMERGENCY MANAGEMENT IN GA TYPE 1 - SSIEM 2015 LYON



18th Postgraduate Course on
Lysosomal Storage Disorders

Nuremberg (Main), Germany
May 29 - June 01, 2019



Programme

Monday, 29 May	Tuesday, 30 May	Wednesday, 31 May
08:30-09:00 Registration and Welcome	08:30-09:00 Registration and Welcome	08:30-09:00 Registration and Welcome
09:00-09:30 Breakfast	09:00-09:30 Breakfast	09:00-09:30 Breakfast
09:30-10:00 Welcome Address	09:30-10:00 Welcome Address	09:30-10:00 Welcome Address
10:00-10:30 Opening Ceremony	10:00-10:30 Opening Ceremony	10:00-10:30 Opening Ceremony
10:30-11:00 Welcome Address	10:30-11:00 Welcome Address	10:30-11:00 Welcome Address
11:00-11:30 Breakfast	11:00-11:30 Breakfast	11:00-11:30 Breakfast
11:30-12:00 Session 1: Lysosomal Storage Disorders	11:30-12:00 Session 2: Lysosomal Storage Disorders	11:30-12:00 Session 3: Lysosomal Storage Disorders
12:00-12:30 Lunch	12:00-12:30 Lunch	12:00-12:30 Lunch
12:30-13:00 Session 4: Lysosomal Storage Disorders	12:30-13:00 Session 5: Lysosomal Storage Disorders	12:30-13:00 Session 6: Lysosomal Storage Disorders
13:00-13:30 Session 7: Lysosomal Storage Disorders	13:00-13:30 Session 8: Lysosomal Storage Disorders	13:00-13:30 Session 9: Lysosomal Storage Disorders
13:30-14:00 Session 10: Lysosomal Storage Disorders	13:30-14:00 Session 11: Lysosomal Storage Disorders	13:30-14:00 Session 12: Lysosomal Storage Disorders
14:00-14:30 Session 13: Lysosomal Storage Disorders	14:00-14:30 Session 14: Lysosomal Storage Disorders	14:00-14:30 Session 15: Lysosomal Storage Disorders
14:30-15:00 Session 16: Lysosomal Storage Disorders	14:30-15:00 Session 17: Lysosomal Storage Disorders	14:30-15:00 Session 18: Lysosomal Storage Disorders
15:00-15:30 Session 19: Lysosomal Storage Disorders	15:00-15:30 Session 20: Lysosomal Storage Disorders	15:00-15:30 Session 21: Lysosomal Storage Disorders
15:30-16:00 Session 22: Lysosomal Storage Disorders	15:30-16:00 Session 23: Lysosomal Storage Disorders	15:30-16:00 Session 24: Lysosomal Storage Disorders
16:00-16:30 Session 25: Lysosomal Storage Disorders	16:00-16:30 Session 26: Lysosomal Storage Disorders	16:00-16:30 Session 27: Lysosomal Storage Disorders
16:30-17:00 Session 28: Lysosomal Storage Disorders	16:30-17:00 Session 29: Lysosomal Storage Disorders	16:30-17:00 Session 30: Lysosomal Storage Disorders
17:00-17:30 Session 31: Lysosomal Storage Disorders	17:00-17:30 Session 32: Lysosomal Storage Disorders	17:00-17:30 Session 33: Lysosomal Storage Disorders
17:30-18:00 Session 34: Lysosomal Storage Disorders	17:30-18:00 Session 35: Lysosomal Storage Disorders	17:30-18:00 Session 36: Lysosomal Storage Disorders
18:00-18:30 Session 37: Lysosomal Storage Disorders	18:00-18:30 Session 38: Lysosomal Storage Disorders	18:00-18:30 Session 39: Lysosomal Storage Disorders
18:30-19:00 Session 40: Lysosomal Storage Disorders	18:30-19:00 Session 41: Lysosomal Storage Disorders	18:30-19:00 Session 42: Lysosomal Storage Disorders
19:00-19:30 Session 43: Lysosomal Storage Disorders	19:00-19:30 Session 44: Lysosomal Storage Disorders	19:00-19:30 Session 45: Lysosomal Storage Disorders
19:30-20:00 Session 46: Lysosomal Storage Disorders	19:30-20:00 Session 47: Lysosomal Storage Disorders	19:30-20:00 Session 48: Lysosomal Storage Disorders
20:00-20:30 Session 49: Lysosomal Storage Disorders	20:00-20:30 Session 50: Lysosomal Storage Disorders	20:00-20:30 Session 51: Lysosomal Storage Disorders
20:30-21:00 Session 52: Lysosomal Storage Disorders	20:30-21:00 Session 53: Lysosomal Storage Disorders	20:30-21:00 Session 54: Lysosomal Storage Disorders
21:00-21:30 Session 55: Lysosomal Storage Disorders	21:00-21:30 Session 56: Lysosomal Storage Disorders	21:00-21:30 Session 57: Lysosomal Storage Disorders
21:30-22:00 Session 58: Lysosomal Storage Disorders	21:30-22:00 Session 59: Lysosomal Storage Disorders	21:30-22:00 Session 60: Lysosomal Storage Disorders
22:00-22:30 Session 61: Lysosomal Storage Disorders	22:00-22:30 Session 62: Lysosomal Storage Disorders	22:00-22:30 Session 63: Lysosomal Storage Disorders
22:30-23:00 Session 64: Lysosomal Storage Disorders	22:30-23:00 Session 65: Lysosomal Storage Disorders	22:30-23:00 Session 66: Lysosomal Storage Disorders
23:00-23:30 Session 67: Lysosomal Storage Disorders	23:00-23:30 Session 68: Lysosomal Storage Disorders	23:00-23:30 Session 69: Lysosomal Storage Disorders
23:30-00:00 Session 70: Lysosomal Storage Disorders	23:30-00:00 Session 71: Lysosomal Storage Disorders	23:30-00:00 Session 72: Lysosomal Storage Disorders



Application to Berlin, Germany
Deadline: April 27, 2019



The actions of Workpackage 7

Website

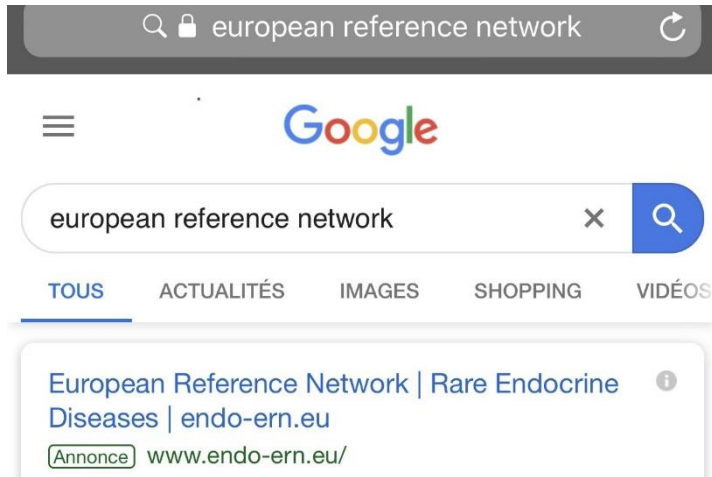


Working method now

- Close Collaboration between WP2 and WP7 by Working meetings with Mireia Del Toro team and Nadia Belmatoug team
- An update and simplification of the website to simplifying the site interface to make it easier to include in the MetabERN portal



On google : MetabERN is in 7th position /24 ERN



European Reference Network LUNG
ERN-Lung › eu

European Reference Networks - Ernica
<https://ern-ernica.eu> › about › european-r...

ERN Skin | European Reference Network for rare
skin diseases
skin.ern-net.eu

European Reference Network – for rare or low
prevalence complex ...
ERN-RND › eu

EpiCARE: a European Reference Network for rare
and complex epilepsies
<https://epi-care.eu>

MetabERN: European Refence Network for
Hereditary Metabolic Disorders
<https://metab.ern-net.eu>

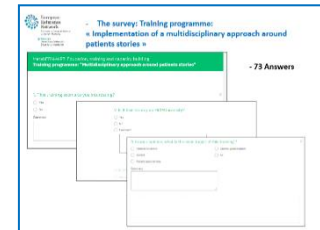


Actions of Workpackage 7

Goal : « Implementation of a multidisciplinary approach around patients stories»

Tool : *Survey*

http://www.metabern-educ.eu/IMG/pdf/survey_monkeyvf0507-1.pdf



Result : *85 % interested*

Decision : present the existing model, formalisation with the HCP and POs involved : « written document», videos then adapt the model country and audience

* Patient consent



Actions of WP 7



Goal : Design and organisation of teaching and training programmes with SSIEM

Transition from childhood to adulthood in inherited metabolic diseases with collaboration of SSIEM .

Tools : 2 meetings in Athen, Mails lists, TCs

Action : organization of a scientific committee



WP7

- Nadia Belmatoug
- Azza Khemiri (French Network of rare metabolic diseases)
- Margaret Giuliani (PO)
- François Eyskens (PD)
- Dominique Rolland (LSD)
- Mireia Del Toro (WP2)

SSIEM

- Andrew Morris (SSIEM academy)
- Manuel Schiff (SSIEM, France)
- Elaine Murphy (Consultant Adult Inherited Metabolic Disease, UK)

WEBINARS

1st webinar: SSIEM-MetabERN collaboration-Webinar on transition from childhood to adulthood 25 April 2019 at 2.30 pm Bruxelles time

2nd webinar: Second webinar on transition - Center of Inherited Metabolic Diseases CEMA UZA Belgium 23th, May 2019 at 2pm30 Bruxelles time







Transition from childhood to adulthood in inherited metabolic diseases
SSIEM-MetabERN collaboration
First webinar

On the European commission webinar platform
 25th April 2019

PROGRAMME

14h30 Nadia Belmatoug, France
Introduction

14h40 Sarah-Jayne Blakemore, UK
Development of the mature brain during adolescence and young adulthood

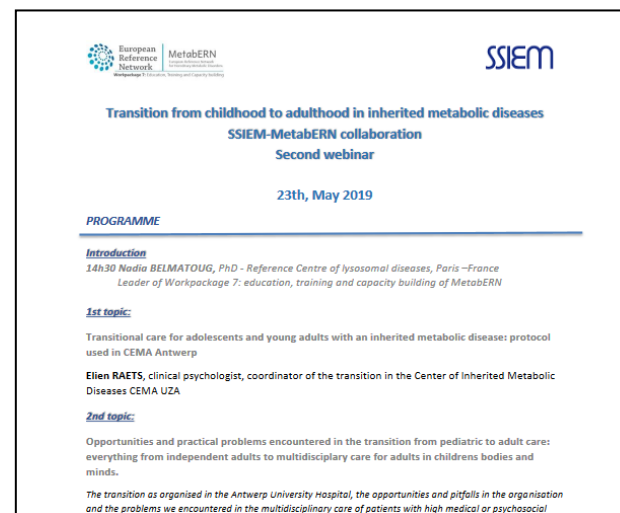
15h Allyson Terry, UK
Case 1: PKU




- Pregnancy planning, teenage, unplanned pregnancy
- Moving out of home, university, etc.

15h20 Nadia Belmatoug, France
Case 2: Gaucher disease, long-term care, monitoring with ERT

15h40 Andrew Morris, UK
Case 3: Patient with learning difficulties, neurodegeneration

- Capacity
- Guardianship
- End-of-life care



Transition from childhood to adulthood in inherited metabolic diseases
SSIEM-MetabERN collaboration
Second webinar

23th, May 2019

PROGRAMME

Introduction

14h30 Nadia BELMATOUG, PhD - Reference Centre of lysosomal diseases, Paris-France
Leader of Workpackage 7: education, training and capacity building of MetabERN

1st topic:

Transitional care for adolescents and young adults with an inherited metabolic disease: protocol used in CEMA Antwerp

Elien RAETS, clinical psychologist, coordinator of the transition in the Center of Inherited Metabolic Diseases CEMA UZA

2nd topic:

Opportunities and practical problems encountered in the transition from pediatric to adult care: everything from independent adults to multidisciplinary care for adults in childrens bodies and minds.

The transition as organised in the Antwerp University Hospital, the opportunities and pitfalls in the organisation and the problems we encountered in the multidisciplinary care of patients with high medical or psychosocial

Collaboration with SSIEM

Futur actions

- 1 member of MetabERN in SSIEM council
- Increase the links via « MetabERN-SSIEM » members
- Umbrella SSIEM-MetabERN
- Collaboration around educational programmes more « patients » centered

The actions of Workpackage 7

- **Goal** : Education around a « clinical rare disease case »
- **Tool** : Quiz of the month: What's your diagnosis?



Quiz of the
month:
What's your
diagnosis?

Action : 1case /year/ each SBN



Actions of Workpackage 7

Understand needs and build capacity among MetabERN patient members and beneficiaries

- Return of the January meeting : improvement of the website

- Surveys in April for Pos on patient education programmes

The image shows a screenshot of a questionnaire form titled "PATIENT ORGANIZATIONS QUESTIONNAIRE". At the top left, there are logos for the European Reference Network and MetabERN. Below the logos, the text "Workpackage 7: Education, Training and Capacity building" is visible. The form contains several input fields: "Patient Organization name:", "Country:", "Contact name:", and "e.mail address:". Below these fields, there is a section titled "A/ Training" with two questions: "1/ Do you have any training organized by your patient organization involved in the field of hereditary metabolic disorders? Yes No

29 associations
8 answers



Questionnaires for the patients organisations April 2019

8 associations/22 : 2 French, 1 Portugal, 1 Spain, 1 Italy, 1 Cyprus, 1 Belgium, 1 German

Programmes : Institutional , 2 with industrial partners

2 diet programmes for patients and families

2 Cooking programmes for patients and families

1 « ventilation » programme for patients and families

1 programme for the dieticians

1 Therapeutic Educational Programme

Priorities :

Education for patients (children), caregivers, dieticians, medical students

Competence, capacity building to built networks

Education for patients to be involved in all steps of care and research

Programmes on physiotherapy, physical training, breathing, nutrition,

Questionnaires for the patients associations

Expectations regarding WP7

Obtaining knowledge in a **lay language**, **better visibility for all diseases** (hierarchy, ultrarare diseases)

Patient centered workshops, conferences with the SSEIM, **parallele MetabERN-SSEIM** session SSEIM meetings

Information on the disease and **recent advances**

Organisation of more HCPs-POs meetings

Replicable models in all EU countries

Validation of PO initiatives

Obtain **support of experts from countries with more experiences and ressources**

Webinars, videos

Resources to organise national workshops

More interaction with WP 2

Expectations regarding the Website

Must be simplified, make it more friendly and a more developed “multimedia”,

more links “Villa Metabolica”, etc.



Action plan 3-5 years



European
Reference
Network

MetabERN
European Reference Network
for Hereditary Metabolic Disorders

Workpackage 7: Education, Training and Capacity building

WP-7 Capacity building and training

Increasing knowledge and skilling up competencies of target groups; supporting Member States to provide highly specialised care to IMD patients

- 7.1 To develop and implement a Therapeutic Education Programme (TEP) for patients
- 7.2 To develop HCP training and teaching
- 7.3 Support to underequipped centres
- 7.4 Expanding the scope of MetabERN

Therapeutic Educational Program

- Very interesting but not implemented in all the countries
- Obligation of certification by health ministry
- Training : physicians, dietician, nurses, patients, etc.
- Other models : kitchen school or informal workshops
- In collaboration with SSIEM
- Training of expert patient by MetabERN or EUPATI and EURORDIS

Action :construction of the model

Action plan 3-5 years



7. Education and Capacity-building													7: Education, Training and Capacity building	
7.1 Therapeutic Education Programme (TEP) for patients													7.1.1 Reach consensus on outcome domains for TEP by using Delphi method	2
													7.1.2 Identify providers of training (stakeholders, training institutions, HCPs etc.) and design of TEP	1
													7.1.3 Implement TEP	3
7.2 HCP training and teaching													7.2.1 Draft a White paper "Adequately meeting the needs of patients: best practices, recommendations, minimum requirements /parameters and outcome domains in setting up of the specialised teaching and training programmes"	3,5
													7.2.2 Develop strategy for an education programme on rare diseases in medical professionals CVs	2
													7.2.3 Identify providers of training (stakeholders, training institutions, HCPs etc.) and design certified training programme	1

Activity/Nr	Year 3				Year 4				Year 5				Linked deliverable(s)
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	
7.3 Support to under-equipped centres													7.3.1 Mapping of availability of training and teaching programme in the under-equipped centres
													7.3.2 Dissemination of best practice programmes to the under-equipped centres
7.4 Expanding scope of MetabERN													7.4.1 Develop exchange programme between MetabERN centres & non-member countries
													7.4.2 Implementation of the exchange programme



Conclusions

Strength

Enthusiastic and reactive partners, nice atmosphere, collaboration with association of patients

Weakness

- Frequently the same HCP and PO who send deliverables
- Lack of resources for webinars, video
- We need help from “SSIEM-MetabERN” strategic members
- Languages, traduction
- Need of an expert in communication

Questions

- Organisation of a university certified educational programme ?
- Do we concentrate on specific metabolic topics ?
- And European Joint Programme for transversal programmes ? >