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

- 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 Francaise des Glycogenoses
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<tr>
<th>Subnetwork</th>
<th>Leader</th>
<th>Members</th>
<th>Country</th>
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<td>Subnetwork 1: AOA</td>
<td>Dries Dobblaere</td>
<td>Anibh Martin Das, Dobblaere Dries, Debray Francois-Guillaume, Javier de las Heras, Francois Eyskens</td>
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<td>Subnetwork 2: C-FAO</td>
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<td>Subnetwork 3: LSD</td>
<td>Dominique Roland</td>
<td>Anne Hugon, Serena Gasperini, Luísa Maria de Abreu Freire Diogo Matos, Ana Maria Simões Mendes Gaspar, Patrício Aguiar, Patrick Deegar</td>
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<td>Subnetwork 4: PD</td>
<td>Eyskens François</td>
<td>Renza Gallupi Barbon</td>
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<td>Subnetwork 5: PM-MD</td>
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<td>Manuel Schiff</td>
<td>France</td>
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<td>Renza Gallupi Barbon</td>
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<td>Subnetwork 6: CDG</td>
<td>Pascale De Lonlay</td>
<td>Nathalie Seta, Arnaud Bruneel</td>
<td>France</td>
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<td>Nathalie Seta, Arnaud Bruneel</td>
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<td>Subnetwork 7: NOMS</td>
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<td>Julia Hennermann</td>
<td>Deutschland</td>
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<td>Patients Organizations</td>
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<td>De Baere Lut, Anne Hugon, Anne-Sophie Lapointe or Christine Lavery, Barbon Renza, Arbellino Cinzia, Ferreira Vanessa, Sproedt Claudia</td>
<td>France</td>
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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
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
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
Educationnal 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
WP-7 Deliverables

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)
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: Multidisciplinary approach around patients stories

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
   - Comment
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
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
Patient Involvement in WP-7

- Good interaction and Collaboration with patients associations

- Some are reluctant to give materials

- Problems of langages and translation

- Avoid redundancy with the work of the associations and Eurordis