



# Work Package 7 Education Training Capacity Building

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## **WP7: Capacity-building & Training**

### **OBJECTIVE:**

- Identification of training and teaching needs as well as already available capacities within the different networks.**
- How they can be used to develop a comprehensive programme for the benefit of participating HCPs, young PhD students as well as patients and their families.**
- One particular focus will be put on capacity-building in affiliated members as well as those centres currently underdeveloped in certain areas.**

## WP7: Capacity-building & Training

### METHODS:

- During the first year, WP7 will focus on the **identification of teaching and training programmes already available to HCPs and patient organisations within the network.**
- The WP will develop **a report on those options available**, including target groups, types of programmes, etc. and provide a short report on their findings to the MetabERN Board, Medical Executive Board, Patient Board and the Advisory Board for consideration.
- Based on the findings and interests of MetabERN members, **a strategy on the provision of training programmes for MetabERN members will be developed in close collaboration with the SSIEM Academy.**
- **An overview of available programmes will be disseminated** through the website as well as through regular updates on upcoming programmes throughout the year.
- **The WP will work closely with WP2, WP5 and WP7**

**WP 2**



## **WP7: Capacity Building and Training**



**WP 5**

**AOA**

**CDG**

**C-FAO**

**PM-MD**

**PD**

**NOMS**

**LSD**

**Collaboration  
SSIEM  
Academy**

### **TARGET GROUP**

**Health Care Professionals, Medical Students,  
Patients, Patients Associations, Dieticians, Paramedics  
etc.**

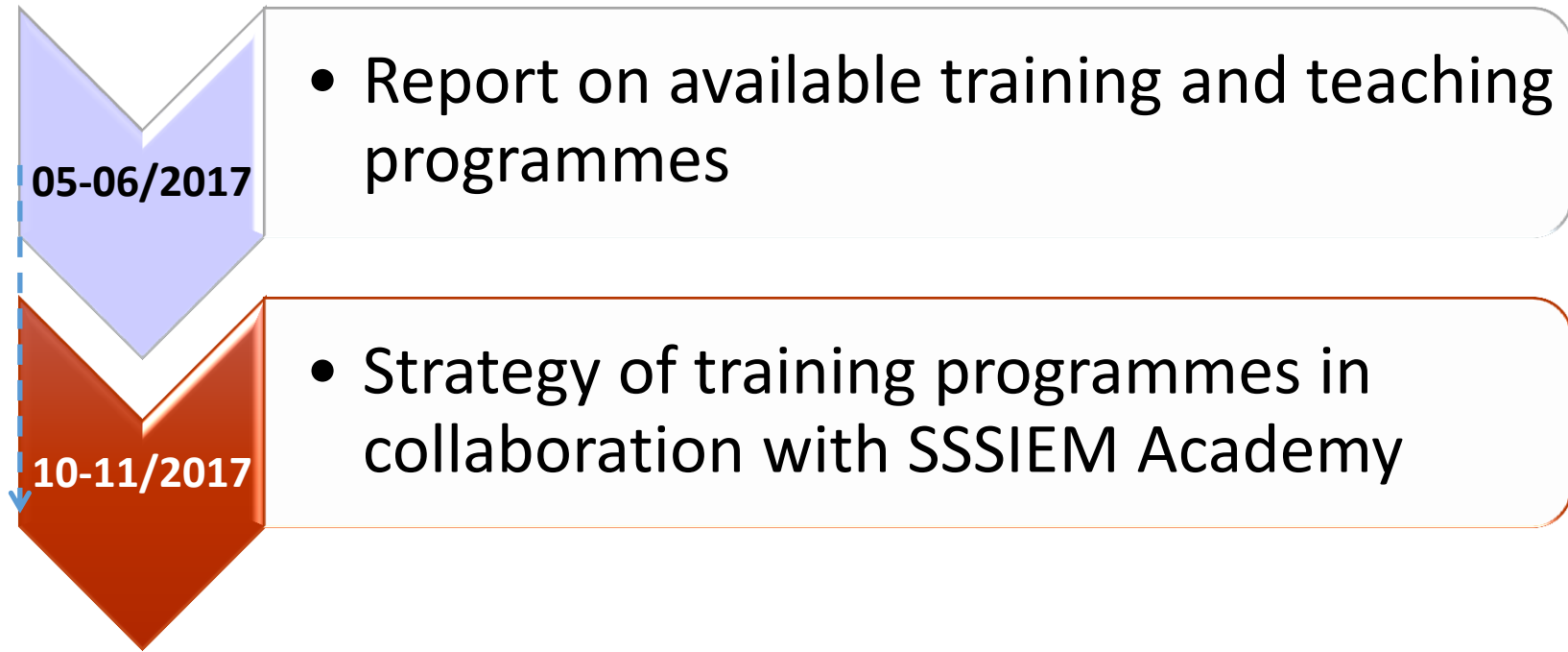
### **RESOURCES**

- Library of courses, digital library
- Standardized teaching programmes, training
- European University diploma in inborn metabolic rare diseases

# WP7: Capacity-building & Training

## Timeline

**For the 1st year**



<b>Report on available training and teaching programmes</b>	<b>05-06/2017</b>
<b>Strategy of training programmes in collaboration with SSSIEM Academy</b>	<b>10-11/2017</b>

# Target groups

- Provide education and training to :

- \* Healthcare professionals
- \* Non healthcare professionals
- \* Patients

**Each target group may become trainers**

# Target group

- **Physicians : students, young experts, experts, specialists, general practitioners**
- **Biologists**
- **Pharmacists**
- **Genetic counselors**
- **Paramedics : nurses, home care, home therapy professionals**
- **Dieticians, psychologists etc;**
- **Clinical research associates and technicians**
- **Scientists**
- **Target future experts and leaders (medical, scientists, researchers)**



# Target group

- **Medico-social and socio-educational actors, school medicine**
- **Researchers in humanities and social science**
- **Representatives of ethics**
- **Representatives of health regulatory authorities, drug regulatory agencies**
- **Medico-economic experts**
- **Representatives of industry**



# Target group

- Association of patients (partnership e-Pag, Eurordis)
  - Patients and families who are not in association of patients
  - Families, other caregivers
- 
- Patients who do not have access to digital tools and devices

## Patient-led activities

Health Hacks  
Workshops  
Conferences  
Consultations  
Round-tables  
Working Groups  
Training Days



Rare Diseases  
eHealth  
Clinical Research  
Health Information  
Health Economics  
Patient Registries  
Biobanking

# Definition of the target group is important to adapt teaching according to the audience

- **Physicians**
- **Students**
- **Scientists**
- **Association of patients**
- **Multidisciplinarity**

**The audience in rare diseases is varied**

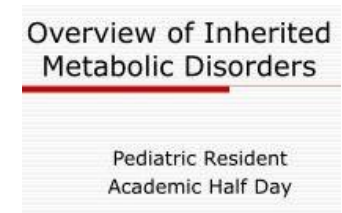
**First step : Inventory of the existing**

**Second step : Building with bridges and links**

# Ressources

- Glossaries : difficult words, acronym, abbreviations
- Reviews : in different format for general public, students, etc.
- Programmes :
  - . *Compile programmes of the medical Societies (SSIEM etc.) : academy, summer school*
  - . *Compile and establish links between societies who are involved and collaborate with SSIEM (MPS society, ESGLD, SSIEM dieticians group, paediatrics societies, genetic societies, etc.*

- Meetings, seminars
- Workshops
- Roundtables



*Some patients, family, caregivers do not use digital tools*

# Ressources

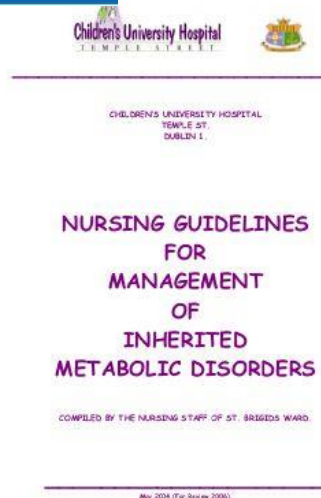
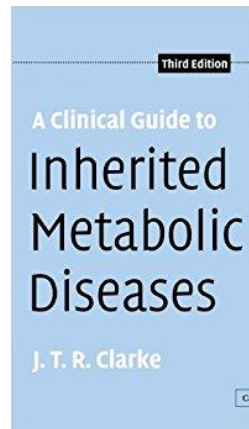
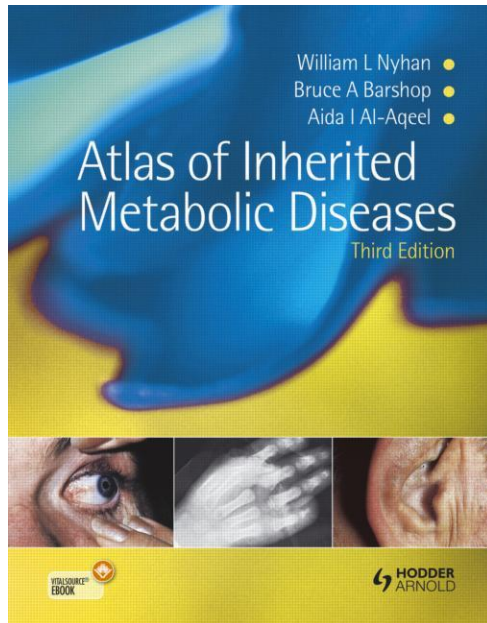
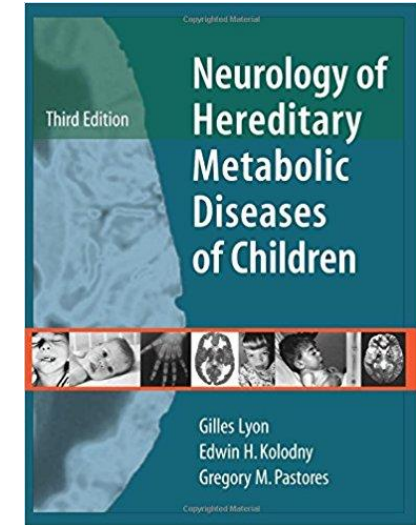
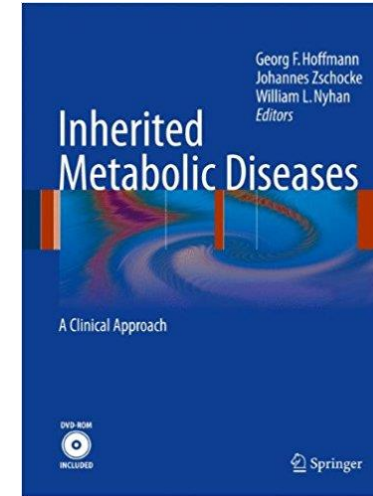
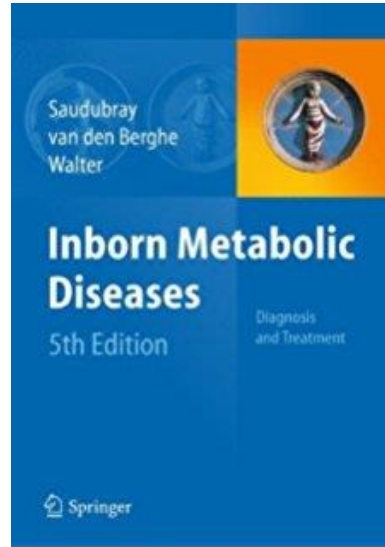
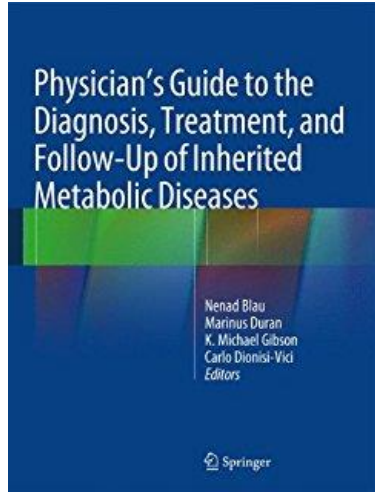
- Continuing professional development for ...lifelong learning

Certification +++

- University degree : Master, PhD, Postdoc



# Ressources : Library



## Ressources : Digital Library



# Ressources

- Quiz and questionnaires on clinical cases
- Quiz and questionnaires to test knowledge
- Slideshows
- Online education courses : webcasts, webinars , webconference
- Tutorial videos
- Participation to virtual consultation with experts
- Commented clinical cases
- Apps, Social networks ?
- Games, comics, films



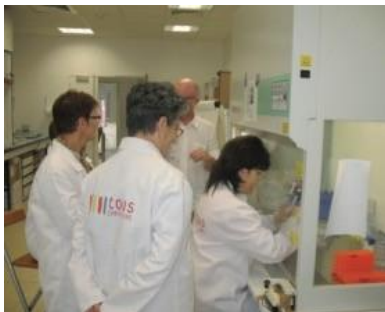
[Tutorial for patients - Know Celli!](#)





# Ressources

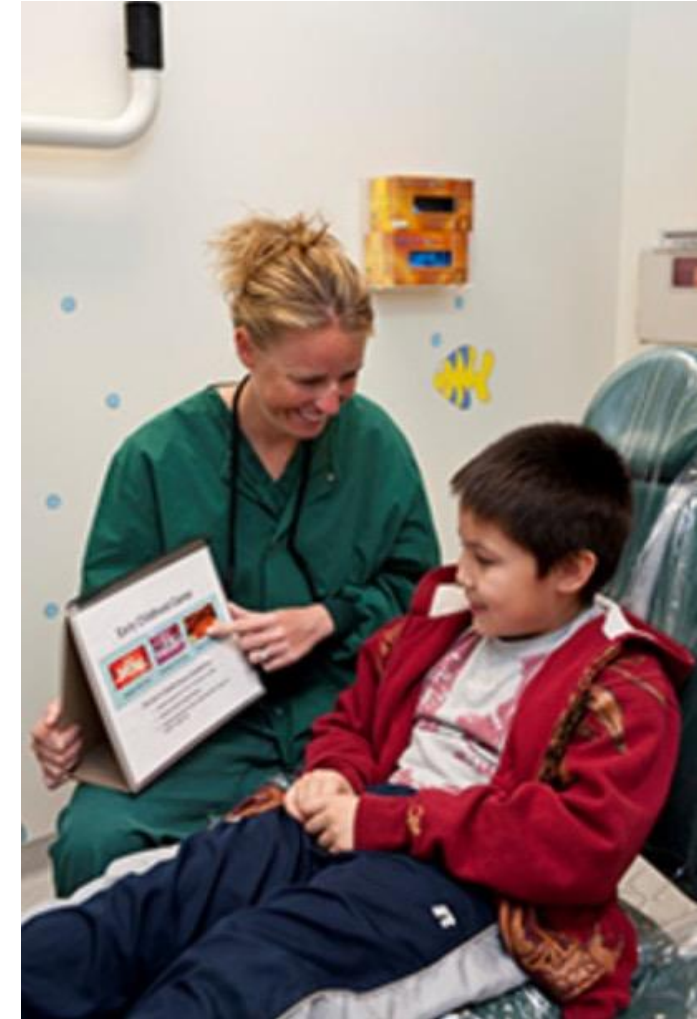
- Training for fellowships, younger clinicians in HCP
- Establishing a list of training HCP, laboratories with specific expertise and training that can receive the applicants to promote exchange of techniques, students
- Learning new techniques, new skills in laboratories, imaging, genetic plateforms
- Letter template available on the MetabERN website for requesting training



# Ressources

## Therapeutic Patient Education Programmes

- Definition
- Existing programmes
- Patient educational materials
- Accessibility
- How to build a TPEP ?



# WORKPLAN

- Establish **an internet portal with all the available materials**

**Programmes must be disseminated**

- Improve knowledge sharing

**Reduce current inequalities in knowledge**

- **Identify goals objectives**

**Methods**

**Timeline**

**Feasibility**

**Sustainability**

**The workpackage must be evaluable : audiences, applicants, training, hours of teaching, web connection**

# Challenges

- **Avoid redundancy and duplication of efforts**

- **Common points between the networks**

- **Common points between the ERNs**

*Announcement of the diagnosis, orphan drugs, devices, reglementary policies, insurance, disabilities, devices, clinical trials, cost of drugs, registries, transition from childhood to adulthood, professional insertion, genetic counselling etc.*

- **Establish equality of access between programmes**

- **Rare diseases pathophysiology leads to better understanding on frequent diseases**

**Establish bridges and links with scientists, basic researchers, physicians who work on frequent diseases**

# Challenges

- **Awareness of the medico-social and socio-educational sector, school programmes**
- **Awareness of new professions :**
- **Knowledge of the patient life course, path**
  
- **Make sure that the knowledge are implemented**
- **Make action to diffuse knowledge, education and training of rare diseases in all societies and educationnal programmes**