



GRUNDTVIG LEARNING PARTNERSHIP

2011-1-RO1-GRU06-14989 1

BOOKLET OF PROJECT RESULTS



TABLE OF CONTENTS

I. THE PROJECT “NEUROMUSCULAR DISEASES: PROFESSIONAL PARENTS AND PATIENTS”	
1. Summary	3
2. Project participants	4
3. Motivation of the project	6
4. Objectives and strategy	7
II. THE PROJECT MEETINGS AND WORKSHOPS	
1. Visit in Romania - 1 st Workshop “Multidisciplinary and collaborative team approach in managing neuromuscular disorders”	9
2. Visit in Italy - 2 nd Workshop: “Facilitating parental participation in multidisciplinary team care of neuromuscular disabled children”	16
3. Visit in Latvia – 3 rd Workshop “Community integration of adults with neuromuscular disability”	22
4. Visit in United Kingdom – 4 th Workshop “Challenges in medical therapies and rehabilitation management of neuromuscular diseases”.	26
5. Visit in Romania – The 5 th Transnational Meeting and Final Event....	31
III. THE PROJECT RESULTS	
1. List of joint results	36
2. Relevance for participants	37
3. Impact on participants	38
4. Swot analysis of the project	38
IV. PROJECT CONCLUSIONS AND RECOMMENDATIONS	39
V. Contacts of the project partner institutions	40

I. THE PROJECT

“NEUROMUSCULAR DISEASES: PROFESSIONAL PARENTS AND PATIENTS”

1. Summary

NMD-PRO is a project working to be a support and information group for parents, patients, and medical/rehabilitation/social care specialists who work with children or adults affected by neuromuscular disorders (NMDs).

The overall objective of this project was to raise and train educative/social/health knowledge and competencies for affected parents or NMD adult patients and transfer these competencies from them to caregivers, for all become a kind of education providers: ‘NMD professional parents and patients’, through an innovative approach in which teachers/learners were both people with personal experience of NMD and care/education specialists.

We wished to find a solution to the general need of knowledge about multidisciplinary management and to establish that family, patient’s needs and perspectives play a pivotal role in educational/research/health programs or social inclusion, thereby covering the topic of supporting disadvantaged learners and people at risk of social marginalization, health education, parent education and inclusive approaches. We promoted demand and motivated adults to learn through the involvement of 5 partners, more than 700 participants and 60 mobilities; we created bridges between informal, non-formal and formal learning through cooperation of a university forming teachers and rehabilitation specialists (RO), two parents associations (RO and UK), a medical and volunteers association (IT), and an adult education provider (LV), which ensured an active cross-border exchange of experience and examples for best practices; we created alternative opportunities to access adult education by the involvement, both as participants and as a target group, of a vulnerable social group (parents and NMD affected adults) in all project activities: planning, implementing and evaluating, consultation, conception and review of developed products;

By putting together all partners capabilities, this project gave us the chance to receive important skills and experiences, both life, cultural and scientific, and generated important results which led to the achievement of Project goals: five Transnational Meetings and four Workshops where we have trained groups of parents, patients, students, care workers, and realization of the project website, Project booklet and the Guide for NMDs parents and patients.

Our project promote a new role for parents, patients and practitioners as “learning advisers” (and the skills needed to fulfil this); this role may be a crucial means of support to enable those who are excluded to reengage in learning, and also encourage them to play an important part as advocates or comprehensive education suppliers.

2. Project participants

Coordinator:



UNIVERSITATEA DIN CRAIOVA (UCV – RO)

University of Craiova (UCV) is situated in the South-Western Region SWR-Oltenia, Romania. UCV is a public institution of higher education, founded in 1947, gaining experience and importance every year. Counting more than 1100 teaching staff members and more than 30000 students, it is one of the biggest Higher Education Institution in RO. Comprises 17 faculties, offering a wide field of study programmes: sports and kinetotherapy (rehabilitation), sciences, humanities, social studies, history, economics, agriculture, law, theology, arts, engineering and so on (33 specializations). UCV organizes Bachelor Degree programmes, Master Degree, Ph.D., in over 70 fields. The Distance learning system is extensively used, especially in the adult education system. UCV is responsible for project coordination, general project management and administration. UCV is involved in the conception of the educational materials in cooperation with people with NMDs, translation into Romanian language, implementation and dissemination activities.

As Coordinator provided technological and linguistics supports to ensure an excellent level results: accomplish the NMD-PRO website and publishing of the Guidebook for NMD professional parent/patient and NMD-PRO booklet.

See more:

<http://www.ucv.ro/>

http://cis01.central.ucv.ro/educatie_fizica-kineto/

Partners:



ASOCIATIA PARENT PROJECT ROMANIA (PP - RO)

The Romanian Parent Project - Association For Muscular Dystrophy Research and Assistance (PP), founded by a group of parents and grandparents of children diagnosed with Duchenne muscular dystrophy, is a non profit organization whose objectives are to establish a Resource Center for Muscular Dystrophies and neuromuscular disorders assistance, funding scholarships for the training of Romanian specialists, to promote contact, communication and exchange of valuable information in the field, to ensure awareness throughout the medical and social community and to inform parents around the country. Since its launch in March 2004, PP's focus has been on the development of tools that clinicians and scientists need to bring novel therapeutic approaches through pre-clinical development and into the clinic, and on establishing best-practice care for neuromuscular patients all over the country. PP RO is also the Coordinator of Romanian DMD/BMD Patient Registry (online database for Romanian patients diagnosed with Duchenne / Becker Muscular Dystrophy), a fundamental tool for obtaining an overview about these diseases and the needs of patients in Romania, with the purpose of closer links between registered patients and medical staff for an easier access to clinical trials regarding new therapies and a better understanding of muscular dystrophies.

As a Partner, PP is involved in all project phases: planning (needs analysis and setting objectives which are promoting the expression of demand), in the conception of the educational materials, dissemination of the project results on a local, regional, national, EU level through its partnerships with the worldwide United Parent Projects Muscular Dystrophy (UPPMD) and TREAT-NMD (the EU funded 'network of excellence' for the neuromuscular field).

See more:

www.parentproject.ro



FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS (FOR - IT)

Fondazione Ospedali Riuniti Ancona (FOR) is a medical and volunteer organization working for Azienda Ospedaliero Universitaria Ospedali Riuniti Ancona (AOU ORA) which will be "third party" of the project. It is a non-profit organization founded on February 2009 inside Ancona University Hospital. FOR was constituted considering that an Ancona University Hospital it is not only a place of care and/or illness, but a complex environment where every day more than 10,000 among professional and citizens share a great quantity of positive human relations: trust, acts of love, passion for work. Fondazione Ospedali Riuniti Ancona has been created to achieve the following objectives:

- 1) To strength and improve quality level of humanization, respect and empathy of the community
- 2) To become "intelligent terminal" looking forward citizens needs
- 3) To improve the quality comfort standards for both patients and their families
- 4) To support the development of scientific research finalized to improve and/or provide care and training
- 5) To improve employees involving because a peaceful and cooperative environment arise better results both on technical and human side.

Fondazione Ospedali Riuniti Ancona, with Azienda Ospedaliero Universitaria Ospedali Riuniti Ancona, is already working in activities of family training of patients both children and adults with neuromuscular disabilities. In order to strength and improve efficiency and efficacy of the structured activities planned for the purpose FOR will take over and share with other partners target group needs, methodologies and best practice. As a NMD-PRO partner, FOR was responsible for organizing the 2nd transnational workshop "Facilitating parental participation in multidisciplinary team care of neuromuscular disabled children", planning, monitoring, data raising, working on all project results and their translation into Italian language, dissemination and mainstreaming activities. FOR IT will incorporate the project activities in to its family/patients training of patients both children and adults with neuromuscular disabilities and volunteers training (professional and citizens tending NMD disabled).

See more:

<http://www.fondazioneospedaliriuniti.it/>



UNIVERSITY EDUCATIONAL CIRCLE (UEC – LV)

University Educational Circle, Latvia, (UEC LV) collaborates with universities, schools and teachers of Latvia and many European countries. It is working in close cooperation with the University of Latvia and educational institutions all over Europe to manage European seminars, courses and projects. Teacher trainers and researchers at the University Educational Circle are from the University of Latvia and have experience as teacher education program directors, teacher trainers and researchers in the field of education. The University Educational Circle collaborates with the Council of Pedagogues of Latvia, Association of Language Teachers of Latvia. The professors and researchers of the University Educational Circle participate actively in the conferences organized by the Association of Teacher Educators in Europe (ATEE) and other international conferences in the field of education. UEC will incorporate project's learning activities into its current training courses, will develop new curriculum in European diversity education and inclusive approaches for teachers, teachers trainers, educational guides and counsellors, headmasters, school policy makers, psychologists, nurses.

UEC was involved in the implementation of all project activities and have the specific responsibility of organizing the 3rd meeting and transnational workshop "Community integration of adults with neuromuscular disability", and as a member of European Teachers Network (ETSsize) will contribute to give an European dimension for NMD-PRO project by adapting the learning materials for primary and secondary schools teachers working with NMDs disabled children and through dissemination activities.

See more:

<http://educationgroup.ucoz.lv/>



ACTION DUCHENNE LIMITED (AD – UK)

Action Duchenne AD (formally PARENT PROJECT UK) is the leading national charity and was established in 2001 to find a cure and promotes education, research and campaigns for better medical care for Duchenne and Becker Muscular Dystrophy. We aim:

- 1) To be a leader in supporting innovative research to cure and treat Duchenne
- 2) To work as a partner with organisations providing resources to help to improve the length and Quality of Life of those living with Duchenne Muscular Dystrophy
- 3) To be led by parents and young people affected by Duchenne and Becker Muscular Dystrophy

Action Duchenne has networks of Parent Action Groups across the UK and Ireland and holds an international conference every year to bring together researchers and families to exchange new research developments and provide a vital meeting venue for scientists. In 2005 Action Duchenne launched the Duchenne Registry www.dmdregistry.org, the first National Duchenne database that holds gene information of people living with Duchenne and can be used to speed up the recruitment of patients for clinical trials. In 2006 Action Duchenne launched a comprehensive learning and behaviour toolkit for use by parents and education professionals and has subsequently launched a national education programme for children with Duchenne. Also through its Race Against Time Campaign it has successfully lobbied the Government to provide improved medical care for those living with Duchenne.

In this project AD is involved in the design of programmes and education to improve the management and medical care for Muscular Dystrophy, will raise awareness of the needs of those living with Duchenne and Becker with UK Governments and policy makers, develops new Campaigns, Projects and disseminates information through Publications and Conferences to promote best practice for Standards of Care. AD is also responsible for the 4th meeting and transnational workshop: 'Challenges in medical therapies and rehabilitation management of neuromuscular diseases' and will integrate the project activities and results into their parents's trainings and adult patients, in its current social, advocacy, clinical, educational programs and campaigns.

See more:

<http://www.actionduchenne.org/>

3. Motivation of the project

The idea ...

- **everybody has something to learn from each other: parents from healthcare and social professionals, specialists from parents and patients, and everyone has to learn from others.**

We have premised that participant learners (parents, patients, teachers, health care and social workers) can be productively involved in formulating agendas for health/social/educational policy and quality based on their own needs and experiences. To produce such statements this Partnership is not only a learning experience in itself, but a basis for negotiation with providers. Through this Project developed and disseminated this principle.

This Learning Partnership focused on demand and motivation by starting with participants's needs analysis and setting objectives which are participant-led and promote the expression of demand. We have also incorporated the needs analysis into project design, relating to the interests not only of all partners, but of a wider range of players (including other providers) and ultimate beneficiaries in terms of target groups and communities.

3. Objectives and strategy

The first objective of our project was to support, train and raise educative/social/health knowledge and competencies for affected parents or NMD adult patients and transfer these competencies from them to caregivers, for all become a kind of educating service providers: "NMD professional parents and patients".

Secondary objectives have been to:

- identify, share and exchange best practices and activities in which each partner has experience regarding social inclusion of neuromuscular disabled people
- introduce the concepts of "family-centered care", "multidisciplinary team care", and "parent-to-parent approach" and their fundamental role in facilitating education, rehabilitation, health care, social programs
- create a website (a future network) to offer free resources to parents, patients and professionals
- improve intercultural competencies, learning and training opportunities used in the member countries and organizations
- contribute to European priorities such as social regeneration, health, family learning.

Our target groups were:

- Parents/families and NMD adult patients
- Health care professionals: medical doctors, kine- and physiotherapists, nurses, psychologists
- Social assistance and care workers
- Educators and teachers
- Volunteers

We wished to **find a solution** to the general need of knowledge about NMD multidisciplinary management and establish that family, patient needs and perspectives play a pivotal role in NMD educational/research/health programs, or social inclusion.



We have achieved the project objectives by:

- tapping the know how of all partners
- the innovative approach in which the teachers/learners are both people with personal experience of NMD and care/education specialists
- through efficient organization for the preparatory work (demands/needs analyze), project activities (meetings and workshops conceptualized for each target group), project outputs: community needs analyze for educational/health/social inclusion policy recommendations, educational materials, Guidebook for NMD professional parent/patient
- by efficient cooperation/evaluation throughout the project: questionnaires and reports (meetings, workshops)

-by direct involvement and participation of all target groups to all activities of the project and inclusion of parents and patients to participate in mobilities, as role models for other learners
-through dissemination and mainstreaming activities: all partners using and adapting their findings, recommendations and good practices in their institutions, and providing opportunities for distributing to community, other organizations and decision-makers, every participant becoming a project multiplier.



II. THE PROJECT MEETINGS AND WORKSHOPS

1. Visit in Romania - 1st Workshop “Multidisciplinary and collaborative team approach in managing neuromuscular disorders”

The first project meeting was held in Craiova, Romania *between 17th and 20th November 2011*. Representatives from all five partners participated. The meeting involved staff and learners, as well as project country coordinators, and provided opportunities for knowing better each other, social events plus cultural visits. A sixth partner, from Spain has withdrawn from the project, and this meant that the project work plan had to be revised.

Participants:

Partner institution	Country	No. of persons	Participant's name
UNIVERSITY OF CRAIOVA (Coordinator) (Host institution)	Romania	7	Eugenia Rosulescu
			Mihaela Zavaleanu
			Ilona Ilinca
			Andrei Anton Tohaneanu
			Taina Elena Avramescu
			Rusu Ligia
			Dan George Pavel
ASOCIATIA PARENT PROJECT	Romania	3	Isabela Tudorache
			Amelia Dobrescu
			Ana Bobirnac
FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS	Italy	2	Roberto Penna
			Samuele Aiello
UNIVERSITY EDUCATIONAL CIRCLE	Latvia	1	Mara Dirba
ACTION DUCHENNE LIMITED	United Kingdom	4	Nick Catlin
			Kate Angus
			Mary Down
			Kathy Wedell

Minute takers: dr. Eugenia Rosulescu, dr. Mihaela Zavaleanu.

Meeting theme and aims:

- to get to know each other (people and partner institutions)
- to have a clear picture of the project, overview of deliverables and upcoming time-schedule
- to discuss any possible changes, difficulties with partners
- to define the frames of activities
- to discuss further milestones and fix the calendar of activities
- to establish the responsibility of each partner and distribution of roles/tasks
- to sign the Mutually agreement of the Partnership

Workshop:

- to give awareness and overview about neuromuscular diseases and multidisciplinary model of care
- know how transfer, exchanging information/experiences and good practices
- to increase knowledge and personal skills of project learners



Work documents:

Each participant has received the following documents needed for the meeting:

1. Meeting Agenda
2. Evaluation Plan
3. Project's work plan for the 1st year
4. List of project's expected results and outcomes for the 1st year
5. Start up Leaflet of the project "NMD-PRO"
6. Meeting Evaluation questionnaire
7. General Partnership Agreement
8. Certificate of Attendance at the 1st NMD-PRO Meeting

The partners have received the documents in English. The meeting has been held in English.

Activities:

Day	Date	Activity
Thursday	17.11.2011	Arrival of the partners at Bucharest airports. Transfer of participants to Craiova to EUROPA hotel. 19.30 For those who arrive early in the afternoon, informal meeting and dinner together.
Friday	18.11.2011	8.00 Breakfast at Europa Hotel 9.00 Official opening of the project meeting and welcome 9.30 Getting known to each other - presentation and introduction of all

		<p>partners and their organisations</p> <p>10.30 Overview of project: Aims and objectives, results</p> <p>11.00 Presentation and discussion of NMD-PRO project:</p> <ul style="list-style-type: none"> - Team building, agreement on ground rules, - Revision of work plan: further milestones and the calendar of activities, confirmation of deliverables and deadlines, - Establishing the responsibility of each partner and distribution of roles/tasks and resources, - Introduction of the project evaluation strategy - Introduction of the project dissemination strategy - Agreement on the project communication system - Signing the "General agreement of the Partnership" - Detailed planning of next steps <p>13.00 Lunch – catering menu at the Faculty</p> <p>14.30 Workshop "Multidisciplinary and collaborative team approach in managing neuromuscular disorders" (part I)</p> <p>17.00 Visit to the City centre / or to University of Craiova, FEFS Department of Sports Medicine and Kinetotherapy</p> <p>19.30 Official common dinner at Perinita Restaurant</p>
Saturday	19.11.2011	<p>8.00 Breakfast at Europa Hotel</p> <p>9.00 Workshop (part II)</p> <p>10.00 Finances, administration, reporting, dissemination: financial issues, interim/final report, internal reporting procedures, website.</p> <p>11.00 Visit to Prefecture of Dolj County, meeting with Mr. Nicolae Giugea, local Government head.</p> <p>Conclusion of Meeting</p> <p>Delivery of certificates of participant.</p> <p>12.30 Departure of our Italian partners</p> <p>13.00 Lunch</p> <p>14.30 Departure to Brasov Region to visit the Valcele Center of neuromuscular pathology</p> <p>20.00 Dinner</p>
Sunday	20.11.2011	<p>09.00 Social and cultural exchange program - visiting the legendary Vlad Tepes (Dracula) Castle in Bran, Transylvania</p> <p>12.30 Common lunch and official closure of the meeting</p> <p>14.00 Travel to Bucharest and departure of partners.</p>



1. ISSUES DISCUSSED

Presentation of the partner organizations to improve the mutual knowledge - each partner presented its own organization and its main activities:

- Mrs. Ligia Rusu presented the host organisation, University of Craiova
- Mrs. Taina Avramescu made a short presentation about LLP projects managed by UCV
- Mr. Roberto Penna and Mr. Samuele Aiello presented Fondazione Ospedali Riuniti Ancona and The University Hospitals of Ancona; also made an analysis of Italian health system regarding NMDs needs
- Mr. Nick Catlin presented the needs and standards of care for NMDs patients, the activities and achievements of Action Duchenne UK
- Mrs. Isabela Tudorache presented us the parents perspective on NMDs and Parent Project RO activities
- Mrs. Mara Dirba presented the educational aspects in NMDs and introduced herself, University Educational Circle and University of Latvia.

Overview of project: aims and objectives, results, timescale

- Mrs. Eugenia Rosulescu made a NMD-PRO Project ppt presentation, which was read by Mr. Dan Paved and debated with all participants.

Discussions and debates on NMD-PRO Project implementation:

- It was debated, revised and established the NMD-PRO Evaluation Plan; all partners agreed to accomplish their own internal and external evaluations
- There were defined the responsibilities and functions of the partners: each partner will involve its local network to implement the activities aimed at collecting and exchanging information and best practices during all the project,
- It was signed the "General agreement of the Partnership" by all partners
- It was revised The work plan and the List of project's expected results and outcomes: further milestones and the calendar of activities, confirmation of deliverables and deadlines:
 - 5 Transnational meetings – hosted by each project partners
 - 12 mobilities for each partner
 - 4 Workshops – organized at the first 4 meetings
 - Learners needs analyze
 - Local activities: documentation, courses, seminars
 - Realization of educational materials and Guidebook for NMD professional parent/patient.
 - Dissemination: local, national, European level

2. PROJECT EVALUATION

Evaluation of outputs

Virtual outputs – It was realised the NMD-PRO project website, nmd_pro Yahoo Group, Nmd-Pro Facebook page

Events - Transnational meeting in CRAIOVA (Romania) was held as planned.

Inaugural event and Management group 1st Meeting

1st transnational Meeting/workshop: 'Multidisciplinary and collaborative team approach in managing neuromuscular disorders'

Products - Start up leaflet of NMD-PRO project, Country Profiles/presentations, Workshop presentations

Evaluation of outcomes

All participant institutions adopted the NMD-PRO project framework

Support from NGOs and agencies

Increased knowledge of participants – staff and learners

- Quality of the transnational element
- Adherence to the aims and objectives of the project
- Flexibility – finding creative solutions to problems

3. WORKSHOP PRESENTATIONS



1st NMD-PRO Project presentation:

Grundtvig Learning Partnerships
 2011-1-RO1-GRU06-14989 1



 Lifelong Learning Programme


 Neuromuscular diseases: professional parents and patients




WHAT IS A GRUNDTVIG PARTNERSHIP?


Grundtvig Partnerships (also known as Grundtvig Learning Partnerships) are small-scale cooperation projects between organisations working in the field of adult education, which decide to work together on one or more topics of common interest.

The focus is on the exchange of ideas and best practice between different organisations across Europe.

The Partnership

-  UNIVERSITY OF CRAIOVA, ROMANIA
-  ASOCIATIA PARENT PROJECT, ROMANIA
-  FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS, ITALY
-  UNIVERSITY EDUCATIONAL CIRCLE, LATVIA
-  ACTION DUCHENNE LIMITED, UNITED KINGDOM

2-year Lifelong learning Grundtvig project for children, their families, adults with neuromuscular disorder.
August 2011 – July 2013

The idea ...

- everybody has something to learn from each other: parents from health care and social professionals, specialists from parents and patients, and everyone has to learn from others.

How ?

- support, training and raising the educative, social, health knowledge and competencies for affected parents or NMD adult patients
- transferring these competencies from them to caregivers, for all become a kind of educational service providers:
"NMD professional parents and patients"

Aims and objectives

- ❖ To introduce the concepts of "family-centered care", "multidisciplinary team care", and "parent-to-parent approach"
- ❖ To identify, share and exchange best practices
- ❖ To create a website (possible a future network) to offer free resources to parents, patients and professionals
- ❖ To create educational materials: Guidebook for NMD professional parent/patient.

Target groups

- Parents/families and NMD adult patients
- Health care professionals: medical doctors, kineto- and physiotherapists, nurses, psychologists
- Social assistance and care workers
- Educators and teachers
- Volunteers

Main activities

- ❖ 5 Transnational meetings – hosted by each project partners
- ❖ 12 mobilities for each partner
- ❖ 4 Workshops – organized at the first 4 meetings
- ❖ Learners needs analyze
- ❖ Local activities: documentation, courses, seminars
- ❖ Realization of educational materials and Guidebook for NMD professional parent/patient.
- ❖ Dissemination: local, national, European

1st year Timescale (I)

DONE:

- Project start date: August 2011
- NMD-PRO Yahoo Group – October 2011
- Project logo - October 2011
- Project start up leaflet and website launched: www.nmd-pro.ro - October 2011
- 1st transnational Meeting/workshop: 'Multidisciplinary and collaborative team approach in managing neuromuscular disorders' – November 2011, ROMANIA

To DO:

- Printed and on-line 1st workshop products – proceedings, report, recommendations, photo gallery - December 2011

1st year Timescale (II)

- Needs analyze of NMD affected children, through the parents/relatives perspectives in the participating countries – March 2012
- 2nd Meeting and transnational workshop: 'Facilitating parental participation in multidisciplinary team care of neuromuscular disabled children' – March 2012, ITALY
- Printed and on-line 2nd workshop products – proceedings, report, recommendations, photo gallery – April 2012

1st year Timescale (III)

- Needs analyze for adults NMD affected - June 2012
- 3rd meeting and transnational workshop: 'Community integration of adults with neuromuscular disability' – June 2012, LATVIA
- PROJECT Interim Progress report (by the end of June 2012) for the NA
- Report/recommendations of the 3rd meeting/workshop: printed and on-line materials – July 2012

This Meeting

To DO:

- get to know each other
- have a clear picture of the project and overview of deliverables
- revise the work plan and calendar of activities
- establish project evaluation strategy
- sign the "General agreement of the Partnership"

Thank you!

Paldies!

Grazie mille!

Multumesc!



Neuromuscular diseases NMDs:

Neuromuscular Diseases - NMD

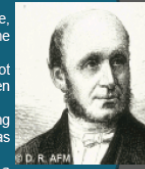


Grundtvig Learning Partnerships
 Project Reference: 2011-1-RO1-GRU06-14989 1
 Project title: NMD-PRO - Neuromuscular diseases: professional parents and patients

History of Neuromuscular Disease

- From Egypt in about 2500 B.C. we have a earliest picture of a child with a muscle disease, which appears to be Duchenne dystrophy.
- Dr. Edward Meryon, who lived in England in the mid-1800s describe for the first time in medical literature a muscle disease: *a child with apparent early-onset muscular dystrophy*.
- The credit for the description of rapidly progressive, childhood muscular dystrophy is given to Dr. Guillaume Duchenne (1806-1875).
- Accurate diagnosis of most neuromuscular disorders was not possible until specific stains were developed, so that frozen muscle tissue could be examined under the microscope.
- New types of neuromuscular disorders are still being identified, predominantly in the group known as **mitochondrial myopathies**.
- The treatment of neuromuscular diseases has changed a great deal over the years as physicians have learned more about lung care and life-support systems.

Guillaume Duchenne de Boulogne (Boulogne-sur-Mer, 1806 - Paris, 1875)



Dr. Duchenne was the first physician to do a muscle biopsy by use of a metal punch, similar to the one that is used in some centers today.

After the work of Dr. Duchene the myology became a new specialty

After the progress of genetics

A better understanding of the physiopathology of neuro-muscular diseases

A possibility of **prenatal diagnosis**

After 2006 start the first gene therapy trials in humans:

Development of diagnosis technics

Improvement of care for the symptoms

What is a neuromuscular diseases?

Neuromuscular diseases is a term that refers to a number of conditions, grouping congenital diseases or acquired that affect muscles and the peripheric nervous system.

There are many different neuromuscular diseases and some of these disorders are difficult to classify under a single heading.

- All of these diseases are mainly characterized by muscle weakness in one form or another.
- The reasons can vary from genetic factors to thyroid problems.

Continuation, and more presentations, can be downloaded from project webpage at <http://nmd-pro.ro/>

2. Visit in Italy – 2nd Workshop: “Facilitating parental participation in multidisciplinary team care of neuromuscular disabled children”

The second project meeting was held in Ancona, Italy, *between 12th and 18th March 2012*, organized by the joint work of Fondazione Ospedali Riuniti Ancona and Azienda Ospedaliero Universitaria Ospedali Riuniti Ancona. Representatives from all five partners participated. The meeting involved staff and learners, and provided opportunities for knowing better the medical/NGO organisation of the Marche region for the NMD diseases, social events plus cultural visits.

Participants:

Partner institution	Country	No. of persons	Participant's name
UNIVERSITY OF CRAIOVA (Coordinator)	Romania	4	Eugenia Rosulescu
			Mihaela Zavaleanu
			Andrei Anton Tohaneanu
			Beldiman Aurora
ASOCIATIA PARENT PROJECT	Romania	4	Isabela Tudorache
			Doru Tudorache
			Bica Daniela
			Iordache Luminita
FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS (Host institution)	Italy	6	Annarita Settimi Duca
			Nadia Storti
			Roberto Penna
			Samuele Aiello
			Ana Ficadenti
UNIVERSITY EDUCATIONAL CIRCLE	Latvia	3	Mara Dirba
			Aili Horna Butkevica
			Arnis Dirba
			Kate Angus
ACTION DUCHENNE LIMITED	United Kingdom	4	Mary Down
			Kathy Wedell
			Ian Clarke

Minute taker: Mr. Roberto Penna

Meeting theme and aims:

- to have an analysis and evaluation of the project, its deliverables and upcoming time-schedule
- to discuss how partners will incorporate the project activities in to them family/patients training for children and adults with neuromuscular disabilities, and volunteers training (professional and citizens tending NMD disabled).
- to analyses target group needs, methodologies and local Italian best practice
- to review any possible changes, difficulties, further milestones and calendar of activities
- to improve intercultural competences, learning and training opportunities used in the member countries and organizations

Workshop:

- to learn how to facilitate parental participation in multidisciplinary team care of neuromuscular disabled children (or patient informed participation in rehabilitation/management team as a decision-maker)
- know how transfer, exchanging information/experiences and good practices

- to increase knowledge and personal skills of project learners



Activities:

Day	Date	Activities
Monday,	12.03.2012	Arrival of the partners at different airports (Rome, Bologna, Ancona).
Tuesday	13.03.2012	Transfer by train of participants to Ancona. Informal meetings and discussions between partners. Social events, visits to Rome or Ancona visit to the City Centre, Conero surroundings.
Wednesday	14.03.2012	Meeting at hotel lobby and informal welcome Work visits of Hospital and NGOs associations involved in healthcare sector

		Time	Place	Activity	
Thursday	15.03.2012	09:00	09:15	Hotel City	Meeting at hotel lobby and walking from hotel to Salesi mother and child hospital
		09:15	09:45	Ex Villa Maria	Meeting at "Aula didattica" for formal welcome
		09:45	10:30		I Session of work Overview of healthcare system in Italy, and Marche Region
		10:30	11:15		II Session of work: paediatric NMD
		11:15	11:30		Coffee break (offered by FONDAZIONE SALESI)
		11:30	12:00		Salesi
		12:00	12:30	Ex Villa Maria	II Session of work: Eventual discussions about visit
		12:30	13:00		Lunch (offered by FONDAZIONE OSPEDALI RIUNITI)
		13:30	14:15	Town Hall	NMD project presentation to Ancona Mayor
		14:30	15:30	Ex Villa Maria	III Session of work NMD and Neuropsychiatry
		15:30	16:00		IV Session of work NMD workplan, first results and best practices individuations
		16:00	16:30	Salesi	Visit to Neuropsychiatry
		18:00	19:30	Ancona centre	Social event: visit to Ancona (Muse theatre)
		20:00	22:00		Social event: Dinner in Ancona (offered by FONDAZIONE OSPEDALI RIUNITI)
Friday	16.03.2012				
		Time	Place	Activity	
		09:00	11:30	Torrette	I Session of work: NMD and Neurorehabilitation
		11:30	11:45		Coffee break
		11:45	14:00		II Session of work NMD discussion about future activities (Aula Zanolì, 4th floor)
		14:00	15:00	Ancona and surroundings	Lunch
16:00	19:00	Social event: visit to Recanati, Loreto and surroundings			
Saturday	17.03.2012	Breakfast at Hotel Departure date for some of our partners. Informal meetings and discussions between partners. Work visits at NGO's involved in children care, rehabilitation, rights protection sector Social and cultural exchange program Official closure of the meeting			
Sunday	18.03.2012	Travel to Rome/Bologna and departure of partners			



Work documents:

Each participant has received the following documents needed for the meeting:

1. Meeting Agenda
2. List of project's expected results and outcomes for the 1st year
3. Meeting Evaluation questionnaire
4. Certificate of Attendance at the 2nd NMD-PRO Meeting

The partners have received the documents in English. The meeting has been held in English.

Working methods:

The 2nd Meeting programme consisted of presentations of the partners, working visits and multiple work shops in small groups at *Azienda Ospedaliero Universitaria Ospedali Riuniti Ancona*, *Clinica Pediatrica* and *Clinica di Neuroriabilitazione*

1. ISSUES DISCUSSED

Presentation of the Italian medical/social model of care and organizations to improve the mutual knowledge:

- discussions and session work Info about welfare in Italy and Ancona
- Roberto Penna NMD-PRO project presentation - he presented Fondazione Ospedali Riuniti Ancona and The University Hospitals of Ancona; also made an analysis of Italian health system regarding NMDs needs
- discussion and 1st session work at Clinica Pediatrica - presentation of Dr Anna Ficcadenti from Rare Diseases Centre, MARCHE; presentation of Dr C. Cardinali, Ospedali Riuniti "G.Salesi", Child Neuropsychiatry Department, Head Physician
- visit to the Ancona City Hall, hosted by the Fiorello Gramillo, the major of Ancona, who who assured us full support for our project

- discussion and 2nd session work at Clinica Pediatrica and visit to pediatric patients
- presentation and discussions with Dr. S. Cappanera – L. Porfiri – about how to facilitate parental participation in multidisciplinary team care of neuromuscular disabled children
- communication of Mr. Filippo Buccella president of DPP - Onlus Italy (Parent Project – DMD) – discussions about their practice, needs and recommendations. DDP has been able to establish a good working relationship with many other organizations worldwide over the years; these networks provide an invaluable asset for a member of the Executive Committee of the TREAT-NMD Alliance. He also aims to collaborate with patient organizations to elicit their suggestions/expectations and to enable him to represent the wider patients' view in the committee.



- work session / visit to the Stroke and Neurorehabilitation Clinic (hospital Maggiore Umberto I, Spitali riuniti di Ancona) where Prof.dr. Maria Gabriella Ceravolo presented us their best practices regarding the multidisciplinary rehabilitation management in NMDs.
- presentation of movement analysis and NESS H200 Hand Rehabilitation System, breathing and assisted suction equipment, opportunities for evaluation of balance in patients with neuromuscular diseases.
- overview of project plan: aims and objectives, results to be achieved from march 2012
- revision of work plan: calendar of activities, confirmation of deliverables and deadlines,
- discussion about the next project evaluation strategy
- discussion about the next project dissemination strategy

- planning of next steps of the project and the next meeting in Riga on July 2012.



2. WORKSHOP PRESENTATIONS


NMD project
 Neuromuscular Diseases: Professional Parents and Patients
 2nd Transnational meeting
 March, 15th - 16th 2012
 Ancona





 Samuele Aiello
 Roberto Penna

Welcome to Ancona and Marche region



2nd Meeting NMD Project
 March, 15th to 16th 2012 - Ancona

Page 3


 Samuele Aiello
 Roberto Penna

Meeting Agenda

09:00	09:15	Hotel City	Meeting at hotel lobby and walking from hotel to Salesi mother and child hospital
09:15	09:45		Meeting at "Aula didattica" for formal welcome
09:45	10:30	Ex Villa Maria	Session of work Overview of healthcare system in Italy, and Marche Region
10:30	11:15		II Session of work: paediatric NMD
11:15	11:30		Coffee break (offered by FONDAZIONE SALESÌ)
11:30	12:00	Salesi	Visit to Clinica Pediatrica
12:00	12:30		II Session of work: Eventual discussions about visit
12:30	13:00	Ex Villa Maria	Lunch (offered by FONDAZIONE OSPEDALI RIUNITI)
13:30	14:15	Town Hall	NMD project presentations to Ancona Mayor
14:30	15:30	Ex Villa Maria	III Session of work NMD and Neuropsychiatry
15:30	16:00		IV Session of work NMD workshop, first results and best practices individualities
16:00	16:30	Salesi	Visit to Neuropsychiatry
18:00	19:30	Ancona centre	Social event: visit to Ancona (Muse theatre)
20:00	22:00		Social event: Dinner in Ancona (offered by FONDAZIONE OSPEDALI RIUNITI)
09:00	11:30		Session of work: NMD and Neurorehabilitation
11:30	11:45	Torrette	Coffee break
11:45	14:00		II Session of work NMD discussion about future activities (Aula Zanoli, 4th floor)
14:00	15:00	Ancona and surroundings	Lunch
16:00	19:00		Social event: visit to Recanati, Loreto and surroundings

2nd Meeting NMD Project
 March, 15th to 16th 2012 - Ancona

Page 4


 Samuele Aiello
 Roberto Penna

Regions in Italy



2nd Meeting NMD Project
 March, 15th to 16th 2012 - Ancona

Page 5

Continuation, and more presentations, can be downloaded from project webpage at <http://nmd-pro.ro/>

3. Visit in Latvia – 3rd Workshop “Community integration of adults with neuromuscular disability”

The third project meeting was held in Riga, Latvia, *between 2nd and 7th July 2012*, organized by University Educational Circle. Representatives from all five partners participated. Staff and learners from different countries participated at the meeting and workshop, visited the National Rehabilitation Centre “Vaivari” to find out what rehabilitation opportunities are offered to NMD patients in Latvia, having the opportunity for knowing better the medical/NGO organisation of Latvia, participating at social events and cultural visits.

Participants:

Partner institution	Country	No. of persons	Participant’s name
UNIVERSITY OF CRAIOVA (Coordinator)	Romania	1	Andrei Anton Tohaneanu
ASOCIATIA PARENT PROJECT	Romania	2	Isabela Tudorache Beatrice Pirvulescu
FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS	Italy	2	Elisa Marconi Roberto Penna
UNIVERSITY EDUCATIONAL CIRCLE (Host institution)	Latvia	3	Mara Dirba Aili Horna Butkevica Ilze Janmere
ACTION DUCHENNE LIMITED	United Kingdom	3	Kate Angus Mary Down Kathy Wedell

Minute taker: Mrs. Mara Dirba

Meeting theme and aims:

- to have an analysis and evaluation of the project, its deliverables and upcoming time-schedule
- to review any possible changes, difficulties and calendar of activities
- to discuss how partners will incorporate the project activities in to them family/patients training for children and adults with neuromuscular disabilities, and volunteers training (professional and citizens tending NMD disabled).



- to analyse target group needs, methodologies and best practices
- to improve intercultural competences, knowledge and skills of the participants

Workshop:

- to facilitate educational, social and health competences of affected parents and educational and health specialists
- know how transfer, exchanging information/experiences and good practices

Working methods:

The 3rd Meeting programme consisted of presentations of the partners, working visits and workshops in small groups.



Activities:

Day	Date	Activity
Monday	02.07.2012	Arrival of the partners
Tuesday	03.07.2012	Informal meetings and discussions between partners. Social events, visits to Riga surroundings.
Wednesday	04.07.2012	Informal meetings and discussions between partners and local inclusive education experts. Social events, visits to Riga surroundings.
Thursday	05.07.2012	9.00 Meeting at the hotel lobby 11.00 -12.00: Session of work at Vaivari Rehabilitation centre 12.30 -14.30 Excursion in Jurmala 14.30 -15.00 Lunch 15.00 -16.00 Information about welfare in Latvia (Riga, Merķeļa 11) 16.00 -17.00 Session of work: NMD patient association „Motus Vita” 17.00 -18.00 Discussion 20.00 - 22.00 Social event: Dinner
Friday	06.07.2012	9.00 Meeting at the hotel lobby 10.00-11.30 Session of work on system of support for learners with different functional disorders in Latvia 11.30-11.45 Coffee break 11.45-13.30 „NMD-PRO – Neuromuscular diseases: professional parents and patients” progress 13.30-14.00 Lunch 14.00- 15.00 Rare disease patient association „Caldrius” 16.00- 17.00 Project partners` presentations on their best practices 17.00 – 18.00 Discussions
Saturday	07.07.2012	Departure date for some of our partners. Informal meetings and discussions between partners.

	Social and cultural exchange program Official closure of the meeting
--	---



1. ISSUES DISCUSSED

- Partners had a learning visit in the National Rehabilitation centre "Vaivari" to find out what rehabilitation opportunities are offered to NMD patients in Latvia. Project partners visited a sensory stimulation room, music and art therapy room, speech therapist and psychologist rooms and different physical therapy and ergotherapy rooms and saw technological support equipment.
- Partners met with NMD association "Motus Vita" manager Valērijs Rakovs who presented his NGO and its role in providing wheelchairs and other necessary technical support tools to NMD patients, organizing summer camps for socialization of NMD patients, participating in international conferences.
- Participants were very interested in the lecture on creating support system for students with functional disorders in Latvia. The lecture was presented by special education expert of Latvia Mudīte Reigase.
- Participants met rare disease association "Caladius" manager Anita Šiklova who presented the role of her NGO in improving situation in diagnosing rare disease patients in Latvia, patient care and rehabilitation.
- MONITORING PROJECT DEVELOPMENT - It was concluded that the Project aims and objectives are being achieved step by step. The partners have done great job for Project publicity. Interviews and questionnaires have been administered to find out patients needs and the situation regarding awareness of NMD in partner countries and identifying problems in providing support for NMD patients and parents in Latvia and other partner countries. Partners' intercultural and diversity management competencies have developed. The partners have shared good practice in educating parents and patients.
- PROJECT EVALUATION - The meeting and workshop were evaluated highly both by Project partners

and invited guests.

2. WORKSHOP

The 3rd transnational workshop “Community integration of adults with neuromuscular disability” was held in Riga, Latvia, more than 30 participants – parents, patients, social workers, teachers, doctors, students, vounteers. The workshop programme consisted of oral presentations and discussions of the partners and participants learners, in small groups.



Workshop presentations can be downloaded from project webpage at <http://nmd-pro/>

4. Visit in United Kingdom – 4th Workshop “Challenges in medical therapies and rehabilitation management of neuromuscular diseases”

and

Action Duchenne 10th International Conference 2012
Friday 9th November and Saturday 10th November
at the Holiday Inn Bloomsbury London WC1N 1HT.

The fourth project meeting was held in London, UNITED KINGDOM, *between 8th and 13th November 2012*. All project partners participated through representatives at the meeting, Conference and workshop. The meeting involved staff and learners, as well as project coordinators, and provided opportunities for knowing better the latest information in the care and treatment research of DMD and other NMD diseases.

Participants:

Partner institution	Country	No. of persons	Participant's name
UNIVERSITY OF CRAIOVA (Coordinator)	Romania	7	Eugenia Rosulescu
			Mihaela Zavaleanu
			Ilona Ilinca
			Mircea Danoiu
			Dan George Pavel
			Sorin Turcu
			Aurora Beldiman
ASOCIATIA PARENT PROJECT	Romania	6	Isabela Tudorache
			Amelia Dobrescu
			Doru Tudorache
			Andreea Vasiliu
			Adrian Croitoru
			Cristian Beschi
FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS	Italy	4	Annarita Settimi Duca
			Elisa
			Roberta Annibali
			Lisa Tonelli
UNIVERSITY EDUCATIONAL CIRCLE	Latvia	1	Aili Horna Butkevica
ACTION DUCHENNE LIMITED (Host institution)	United Kingdom	5	Nick Catlin
			Kate Angus
			Mary Down
			Katherine Wedell
			Iain Clarke

Minute takers: Kate Angus, Mihaela Zavaleanu

Meeting theme and aims:

- to evaluate the project, review deliverables and upcoming time-schedule
- to discuss any possible changes, difficulties with partners
- to discuss further milestones and fix the calendar of next activities
- study visit to relevant places.
- meeting with specialists and staff in relevant institutions

Workshop and Conference:

- know how transfer, exchanging informations and good practices

- to learn and understand the progress of genetic research following AD major launch of the *skipDuchenne* research programme
- to share the successes of AD *Boys to Men Campaign* and the continuing need to bring about best medical care for those living with Duchenne
- to discuss how we can improve transition to adult services
- to learn about the *Takin' Charge Project* and support the psychosocial care of young people and their families
- to increase knowledge and personal skills of project learners



Activities:

Day	Date	Activity
Wednesday	07.11.2012	Arrival in London of the partners at different airports Informal meetings and discussions between arrived partners and host organization members.
Thursday	08.11.2012	Arrival in London of the partners at different airports Informal meetings and discussions between partners. For those who arrive in the previous day, visit to the host institution, in afternoon informal meeting and dinner together.
Friday	09.11.2012	8.00 Breakfast at hotel 9.00 Official opening of the project meeting and welcome Participating to the Action Duchenne Conference

		Conference webpage: http://www.actionduchenne.org/r-nav/655.jsp
Saturday	10.11.2012	8.00 Breakfast at Hotel 9.00 Participating to the Action Duchenne Conference Conference webpage: http://www.actionduchenne.org/r-nav/655.jsp
Monday	11.11.2012	Social and cultural exchange program – visiting London, boat ride on Thames River to the Royal Observatory Greenwich
Tuesday	12.11.2012	9.00 Project meeting - continuation 9.30 Review of project: Aims and objectives, results 11.00 Presentation and discussion of NMD-PRO project: - Revision of work plan: further milestones and the calendar of activities, confirmation of deliverables and deadlines, - Detailed planning of next steps 13.00 Lunch 14.30 Workshop "Challenges in medical therapies and rehabilitation management of neuromuscular diseases" (part I) 19.00 Free dinner
Wednesday	13.11.2012	9.00 Workshop "Challenges in medical therapies and rehabilitation management of neuromuscular diseases" (part II) 12.00 Lunch 14.00 Informal meetings and discussions between partners. Work visits at NGO's involved in children care, rehabilitation Social and cultural exchange program Official closure of the meeting Departure date for some of our partners.
Thursday	14.11.2012	Departure of partners.

Working methods. The 4th Meeting programme consisted of presentations of the partners, working visits, discussions and workshops in small groups during and after participation at the International Duchenne Conference.





1. ISSUES DISCUSSED

- The Conference has highlighted the progress of genetic research following our major launch of the skipDuchenne research programme. The Conference has also highlighted the successes of our Boys to Men Campaign and the continuing need to bring about best medical care for those living with Duchenne. Also, the speakers present ways to improve transition to adult services, Takin' Charge and support the psychosocial care of young people and their families.

- Speech of interest for the participants were:

- Martin Bashir Broadcaster whose brother Tommy had Duchenne
 - Professor Francesco Muntoni iDESC, UCL and GOSH - Progress of exon skipping trials and research
 - Pdraig Wright GSK GSK2402968 exon 51 skipping antisense oligonucleotide – current status and future steps
 - Giles Campion - Prosensa NL
 - Professor Matthew Wood and Dr Mike Gait - University Oxford and Cambridge - Improving delivery of exon skipping oligomers
 - Dr Ed Kaye AVI Biopharma US - Results of the Phase 2B Eteplirsen 48 week extension trial
 - Dr Keith Foster University of Reading - Gene replacement using AAV viruses
 - Dr Luis Garcia - France - AAV delivery of exon skipping
 - Dr Rob Kotin NIH USA - Production of AAV viruses
 - Dr Nick Hart Lane Fox Unit London - A Multi-Disciplinary Approach to the Respiratory Care of Patients with Complex Progressive Neuromuscular Disease
 - Professor Giulio Cossu UCL London - A phase I/II trial of cell therapy for DMD
 - Dr Jenny Morgan UCL London - Stem Cell Therapy for Duchenne
 - Marion Main GOSH Physiotherapy
 - Sunil Rodger - Care NMD Report
- Oral presentations of the each partner impressions after the conference participation regarding the new information in the area of the treatment of NMD and specially Duchenne dystrophy.
- There were formulated new ideas for the NMD-PRO booklet and for the project Guide for parents/patients.
- It was revised The work plan and the List of project's expected results and outcomes: further milestones and the calendar of activities, confirmation of deliverables and deadlines:
- 5 Transnational meetings – hosted by each project partners
 - 12 mobilities for each partner
 - 4 Workshops – organized at the first 4 meetings
 - Learners needs analyze
 - Local activities: documentation, courses, seminars

2. WORKSHOP

The 4th workshop "Challenges in medical therapies and rehabilitation management of neuromuscular diseases" brought together more than 30 participants – parents, patients, social workers, teachers, doctors, students, vounteers. The workshop programme consisted of oral presentations and discussions of the partners and participants learners, in small groups.



5. Visit in Romania – The 5th Transnational Meeting and Final Event

The 5th project meeting was held in Craiova (Faculty of Physical Education and Sports, Brestei str, no.156), Romania between 20th and 23rd June 2013, being organized by the joint work of Parent Project Association and University of Craiova. *Representatives from four partners participated.* The other 5th partner - University Educational Circle (LV) completed its own 12 mobilities during the Work Visit in Italy, Ancona, last year (8th-13th July 2012); they participated to our meeting discussions on a Skype Conference.

The meeting involved staff and learners from all 4 participant partners, and provided opportunities for project quality final evaluation, for drawing conclusions and recommendations.

Participants:

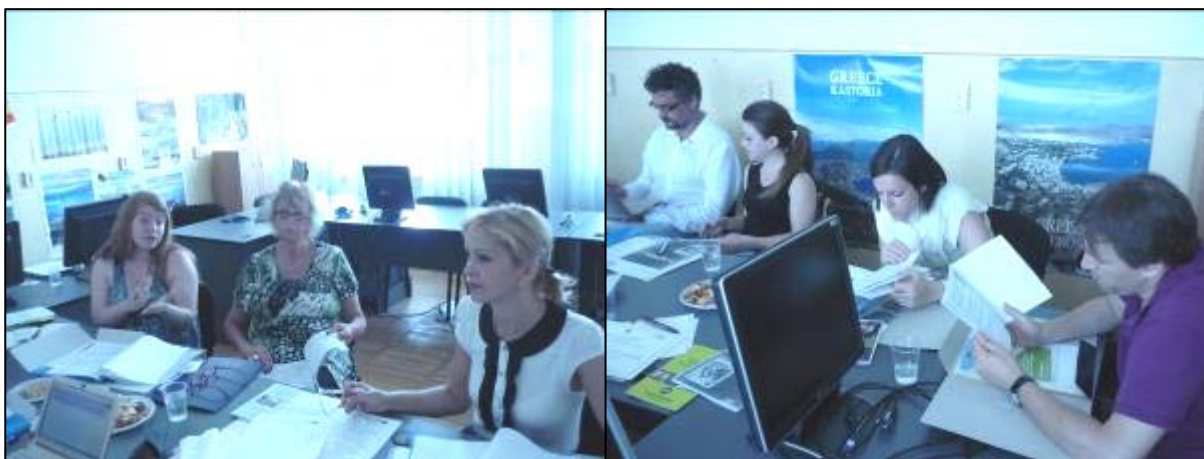
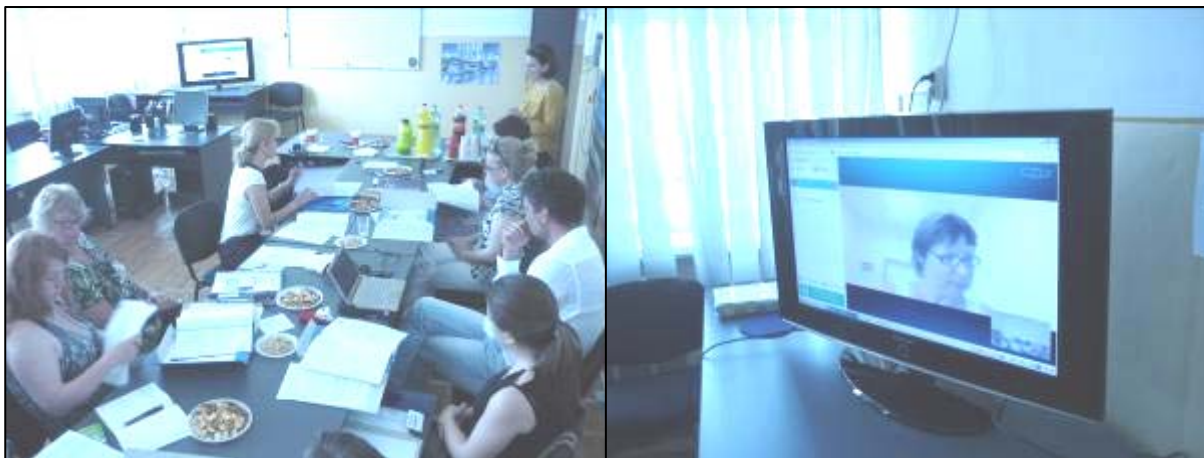
Partner institution	Country	No. of persons	Participant's name
UNIVERSITY OF CRAIOVA (Coordinator) (Host institution)	Romania	10	Eugenia Rosulescu
			Mihaela Zavaleanu
			Iлона Ilinca
			Costi Nanu
			Germina Cosma
			Aurora Beldiman
			Alina Albina
			Sorina Cernaianu
			Mirela Shao
			Emanuele Leoni
ASOCIATIA PARENT PROJECT (Host institution)	Romania	4	Isabela Tudorache
			Amelia Dobrescu
			Adrian Croitoru
			Tudorache Tudor
FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS	Italy	4	Roberto Penna
			Elisa Marconi
			Giada Del Baldo
			Marco Manna
ACTION DUCHENNE LIMITED	United Kingdom	2	Kate Angus
			Mary Down

Minute takers: dr. Eugenia Rosulescu, dr. Mihaela Zavaleanu.

Meeting theme and aims:

- to analyze the results of each partner and the common of the Partnership
- to complete and prepare for publication the Guidebook for NMD professional parent/patient and NMD-PRO booklet
- to collect materials for final evaluation/report and work together on the Final Report and recommendations
- to complete the final evaluation questionnaires and quality/quantitative evaluation
- to draw conclusions and recommendations for decision-makers and stakeholders
- to review the changes, difficulties, and activities

Working methods The 5th Meeting programme consisted of discussions and presentations of the country coordinators; debates, reflective talks, and feedback of participants.



Activities:

Day	Date	Activity
Thursday	20.06.2013	Arrival of the partners at Bucharest airports. Transfer of participants to Craiova hotel. 19.30 For those who arrive early in the afternoon, informal meeting and dinner together.
Friday	21.06.2013	9.00 Official opening of the project meeting and welcome 9.30 Presentation of all partners and their organisations tangible/quantitative results (needs analyses, local workshops/seminars, printed and on-line educational materials, newspaper/journal/conference/web articles) and intangible results : project outcomes in terms of satisfaction/impact on target groups, increased knowledge level of individuals, changes in attitude, cultural awareness derived from a mobilities, impact/benefits at institutional level 11.00 Analyze, prepare, complete of NMD-PRO project common results – Guidebook for NMD professional parent/patient, the NMD-PRO booklet/report, website, etc. 13.00 Press conference 13.30 Common Lunch at Perinita Restaurant

		 <p> 14.00 Finances, administration, reporting, dissemination: financial issues, final report, reporting procedures, website etc. 17.00 Visit to the City centre, University of Craiova, FEFS Department of Sports Medicine and Kinetotherapy. 19.30 Common dinner </p>
Saturday	22.06.2013	<p> 10.00 Visit to "Colt de Rai", Bulzesti area (30 Km from Craiova) to a specific traditional Romanian zone. Reflective discussions and analyses between UCV, PP RO and UK participants regarding the Project impact on their institutions and learners (parents, patients, students) </p>
Sunday	23.06.2013	<p>Travel to Bucharest and departure of partners.</p>



Work documents:

Participants received the following documents needed for the meeting:

1. Meeting Agenda
2. Meeting Evaluation questionnaire
3. Certificate of Attendance at the 5th NMD-PRO Meeting
4. 1st Draft of *Project final evaluation report – printed/electronic form*
5. Draft of *NMD-PRO Booklet of results – printed/electronic form*
6. Draft of *NMD-PRO Guidebook for parents/patients – printed/electronic form*
7. A CD with all project common results in electronic form

The partners have received the printed and electronic documents in English.
The meeting has been held in English.



1. ISSUES DISCUSSED

Each partner presented its own organization results and its main activities:

- Mrs. Eugenia Rosulescu presented the University of Craiova results and achievements
- Mr. Roberto Penna presented Fondazione Ospedali Riuniti Ancona and The University Hospitals of Ancona
- Mrs. Kate Angus presented the activities and achievements of Action Duchenne UK
- Mrs. Isabela Tudorache presented us the parents perspective on NMDs and Parent Project RO activities
- Mrs. Mara Dirba presented, by Skype connection, the UEC point of view about common results, their work visit in Ancona, their local results – seminars, workshops and dissemination

Overview of project: results, timescale

- Mrs. Eugenia Rosulescu presented The Project Booklet of Results/report and debated with all participants.



Discussions and debates on:

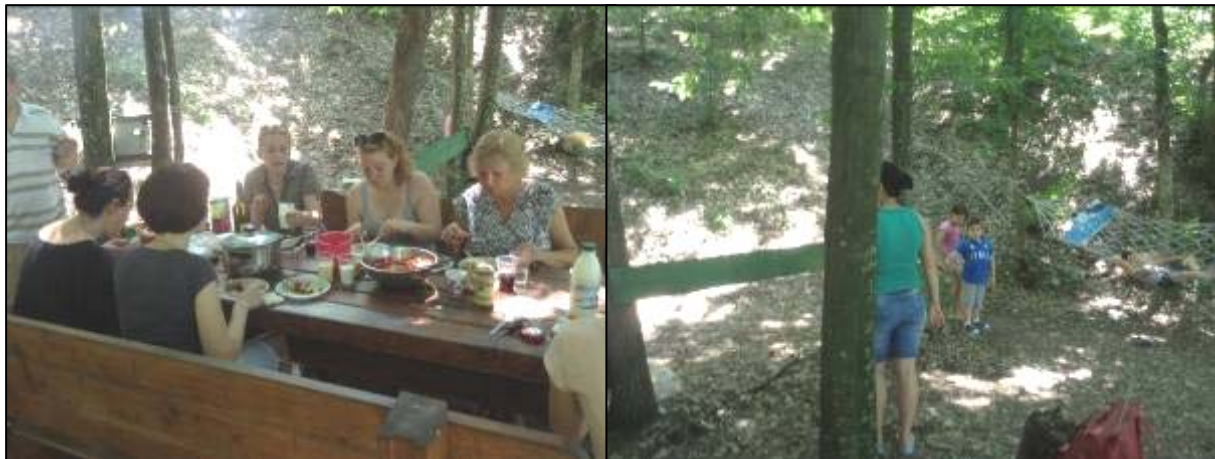
- NMD-PRO Project relevance for each partner, impact on staff, trainers and learners, implementation, dissemination and future exploitation
- It was evaluated and revised the List of project's expected results and outcomes, confirmation of deliverables and deadlines:
 - 5 Transnational meetings – hosted by each project partners
 - 12 mobilities for each partner

- 4 Workshops – organized at the first 4 meetings
- Learners needs analyze
- Local activities: documentation, courses, seminars
- Realization of educational materials and Guidebook for NMD professional parent/patient – ready to be printed by the end of June 2013
- Dissemination: local, national, European level

2. PROJECT EVALUATION

There were evaluated:

- Meetings/Workshops
- The common results
- Each partner results and achievements
- Evaluation of project implementation
- Quality of the transnational element
- Adherence to the aims and objectives of the project
- Flexibility – finding creative solutions to problems



3. DECISIONS MADE

WORK PLAN FOR NEXT YEARS/PROJECT EXPLOITATION AND MULTIPLICATION:

- Project recommendations to be send/debated with all possible decision-makers
- Future collaboration between project participants on the same themes: parent/patients health education, students/practitioners education for a collaborative approach of care
- Future common projects: to participate at 2013 International Action Duchenne London Conference, Erasmus projects, LLP European Multilateral projects
- Dissemination of the project results in all participating countries

III. THE PROJECT RESULTS

1. List of joint results

By putting together all our capabilities to reach a good friendship and profitable collaboration, this project gave us the chance to receive important skills, both life, cultural and scientific experiences. The project therefore generated:

1.1. Tangible results:

Project Website. This is one of the main project outputs where all participating institutions have contributed based on their experiences. NMD-PRO website can be found at <http://nmd-pro.ro/> , comprising Front page, Project Description page, Project Documents page, Partners page, Meetings page, Photo Gallery and Forum. It contains all information about what has been realized and what has been produced. [Link to: http://nmd-pro.ro/](http://nmd-pro.ro/)

NMD-PRO Facebook page. can be found at <https://www.facebook.com/pages/Nmd-Pro/284803428220205>

Project Major Events. Five Transnational Meetings and four Workshops on various topics related to project issues. [Link to: http://nmd-pro.ro/](http://nmd-pro.ro/)

Start up leaflet of NMD-PRO project. It is a dissemination brochure comprising and presenting essential informations about the Partnership, project logo, the partners, project summary, premises, targeted issues and groups, objectives and approaches, the project main events (meeting and workshops). [Available at http://nmd-pro.ro/](http://nmd-pro.ro/). [Directly downloadable.](#)

Project logo. The project logo, as shown on the front page of this booklet and on all project documents, is the result of all partners' contribution. The logo was chosen after market testing across the partner countries. The outline hemicycle (crescent) of the logo represents the union of the project participants around the globe and the project acronym; the globe (Earth) is circled by another small green globe (as the atom gravitating around nucleus) representing one of the millions of persons affected/related by NMDs from the project target groups. [Directly downloadable.](#)

Tools and templates for project implementation. They are drafted in Microsoft Word or Adobe Reader program, A4 shaping, and can be used as an example of good practice for many other projects: Project evaluation plan, Meeting invitation form, Meeting attendance list form, Meeting evaluation form, Minutes - Meeting Report form, Workshop Attendance List, Work plan 1st year, Planned results 1st year, Partner Internal Monitoring Form, Common Internal Monitoring Report. All documents can be downloaded from NMD website. [Link to: http://nmd-pro.ro/](http://nmd-pro.ro/)

NMDs Educational Needs Questionnaire. We presented this questionnaire as a research paper at the 5 International Conference: PHYSICAL EXERCISES - A COMPLEX AND MODERN WAY TO PROMOTE HEALTHY LIVING, Craiova 29-30 March 2013, and published "Needs analysis of lifelong learning on neuromuscular diseases for Romanian participants to NMD-PRO Project" in Journal of Sport and Kinetic Movement, p.174-180, no. 21, vol. 1/2013, a biannual publication, who appeared for the first time in 2004 (formerly Journal "Viitorul"), being recognized by the National Council of Scientific Research from Romania. <http://cis01.central.ucv.ro/exercitiulfizic/files/program.pdf> or http://cis01.central.ucv.ro/educatie_fizica-kineto/pdf/archive.pdf . [Directly downloadable.](#)

Meeting reports. After each meeting of the project was published a report of the meeting activities. The report was sent to each partner organization. [Available at http://nmd-pro.ro/](http://nmd-pro.ro/). [Directly downloadable.](#)

First workshop presentations. 1st workshop "Multidisciplinary and collaborative team approach in managing neuromuscular disorders", held in Craiova, Romania; more than 100 participants – parents, patients, teachers, doctors, physical therapists, students, volunteers. [Available at http://nmd-pro.ro/](http://nmd-pro.ro/). [Directly downloadable.](#)

Second workshop presentations. 2nd transnational workshop "Facilitating parental participation in multidisciplinary team care of neuromuscular disabled children", held in Ancona, Italy; more than 40 participants – parents, patients, teachers, doctors, physical therapists, students, volunteers. Available at <http://nmd-pro.ro/>. Directly downloadable.

Third workshop. 3rd transnational workshop "Community integration of adults with neuromuscular disability", held in Riga, Latvia, more than 30 participants – parents, patients, social workers, teachers, doctors, students, volunteers. The workshop programme consisted of oral presentations and discussions of the partners and participants learners, in small groups. Available at <http://nmd-pro.ro/>. Directly downloadable.

The fourth workshop. 4th transnational workshop "Challenges in medical therapies and rehabilitation management of neuromuscular diseases", held in London, UK after participation at the Conference; the workshop programme consisted of oral presentations and discussions of the partners, in small groups; more than 30 participants. Project participants had the opportunity to participate at Action Duchenne 10th International Conference 2012 (Friday 9 and Saturday 10 November), more than 500 participants. Link to: <http://www.actionduchenne.org/conference2012>

Project final evaluation report. This Report is a valid form of quality assurance and quality development of the project. By these means we hoped to optimize the progress of the project. Evaluation activities were coordinated by the Univ. of Craiova with the participation of all partners, mostly choosing instruments that made internal perspectives of the people involved visible at once, so that results could be used immediately for further work. Some instruments were based on reflection and feedback. It can be found on the project website <http://nmd-pro.ro/> . Directly downloadable.

NMD-PRO Booklet of Project Results. This is one of the main outputs, a Project Report comprising a synthesis of the partnership, meetings and workshops, project results, impact and relevance for participants, project swot analysis, conclusions and recommendations to patients, parents, health and social care specialists, community, other organizations and decision-makers. It can be found on the project website <http://nmd-pro.ro/> . Directly downloadable.

Guidebook for NMD professional parent/patient. We have created a this educational material, that will support NMDs affected patients or parents and anyone seeking to develop more knowledge about these disabling disorders, about what it means the multidisciplinary team management, family-centered care and parent-to-parent approach. It is currently available on the website - <http://nmd-pro.ro/> . Directly downloadable.

Intra-/interinstitutional dissemination. Each partner organized an introductory presentation of the project to prospective participants, some had meetings with local municipalities (Romania, Italy), we created several drafts for a project logo and agreed on one of them, we created the first project leaflet, available in all partner's languages, and all partners published online articles or in newspapers and partners websites.

1.2. Intangible results:

Exchange of good practices: in the frame of mobilities, we visited structures of medical care, social care, special education, NGOs in the partner countries. Aim was to know the situation of each country, to meet good practices etc and to test if we can adapt solutions for our local reality.

Raised awareness in the local target groups and community.

Upgraded skills of learners demonstrated by interviews or analyses through questionnaires.

More fluent and better English language competence and communication skills for all the participants.

Enhanced participants' knowledge of the culture, society, health issues and social systems of project member countries.

2. Relevance for participants

This learning partnership promoted European cooperation in the field of adult education between trainers and learners from different European countries. This cooperation offered the participants an opportunity to exchange experiences, practices and methods in their daily life and at work, that otherwise would not have been achieved at a national level.

We have addressed to a relevant subject: the topic of supporting disadvantaged learners and people at risk of social marginalization as those with NMDs special needs and disabilities, health education, parent education and inclusive approaches, through an innovative teaching-learning

method based on learners needs analysis and promoting the expression of demand, in which the teachers/learners are both people with personal experience of NMD and care/education professionals, project results being transferable to other adult training providers including NGOs, consultants, universities, colleges, and authorities responsible for healthcare and social services.

The partners' experiences completed each other. The added value of this multi-country partnership is reflected in the cooperation and reunion of these different experiences. The common work in the project added value to the activities of each partner institution, giving them the possibility to improve their knowledge and efficiency through transnational activities. Thus, different organisations from Europe have put together human and financial resources and complementary expertise to solve a common problem much better than they would have done it alone, locally.

3. Impact on participants

We increased our participants knowledge by gaining on scientific rigour, quality standards, perspective, methodology, and expertise, project management skills, logistical skills and professional financial administration. This project provided us a gateway to other relevant knowledge and competencies as well as wide ranging and relevant networks.

NMD-PRO Project acted for all partners as a staff/learners development tool and generates new skills, knowledge and personal growth in the people who participate directly.

At institutional level, it brought meaningful networking with both familiar and trusted partners as well beyond through the development of new relationships. It also brings social awareness and a fresh perspective (at European level) and encouraged efficiency, effectiveness and lean management practice, and the final project results provided new teaching and learning tools and materials.

4. Swot analysis of the project

Strengths:

1. The improving of experiences
2. Great cooperation and friendship
3. Discussions/knowledge gain about patients, parents' and children's problems
4. Attraction of learners (parents, students, trainers, volunteers) to the other cultures
5. Possibility to transmit the project to other countries
6. Solving of activity quality problems
7. Supported by EU Funding
8. Project development to create new educational bridges

Weaknesses:

1. Lack of English language skills of all participants
2. Difficulties of communication with project participants on time
3. Difficulties in using the yahoo.group and project facebook page
4. Lack of a higher financial support for the needs requirements
5. Difficulties in finding a suitable time to arrange meetings between the participating countries

Opportunities:

1. To find more partners
2. To invite parents/patients/volunteers to workshops and to take care of them
3. To expand the project
4. To learn about different cultures, traditions
5. To communicate with NGOs in different countries
6. To learn other languages
7. To find ideas for new projects

Threats:

1. Different languages as a problem for communication
2. Differences in local law and management
4. Short time for project implementation activities
5. Different profiles of participants
6. Different interests of participants

IV. PROJECT CONCLUSIONS AND RECOMMENDATIONS

Some NMDs are very rare, while others are more widespread. The number of people affected by neuromuscular disorders is seriously underestimated; consecutively the number of carers, as parents, relatives and friends is significantly greater than the number of people becoming NMD impaired. These people are spread far and wide across the EU and for most of them there are few provisions.

The primary objective of the project was to help these people and set them on a path of management through guidance, advice and training. This partnership project exists to find the disparate target audience in the partner countries and make sure they are aware of the benefits offered by the project.

The participation in this project meant to put together different capability to reach a good harmony, friendships, transnational and profitable collaborations on the thematic proposals. Through this Project we tried to find a way to make compulsory for hospitals/social services to give parents the necessary support and informations to assimilate that their child is special, give guidance in the treatments available for the child's pathology, to offer them a guide of centres for treatment, of centers for support from NGOs, support and how to access them if there are any available, information on networks of families in similar situation. But specially the emotional support to accept the gift of taking care of the development of a special human being.

By pursuing both strands of the target audience it is expected that the project will serve as much of the target audience as possible, in the initial round. It is also expected that the project will assist in the setting up support groups where they have not existed before and through them, promote the project further.

Practitioners need more information about basic genetics, genetic counseling, supports and therapies for particular disorders, as families will be searching for this kind of information. But this knowledge no longer belongs solely to the professionals. The parents and patients may know more than most professionals about their child's specific genetic disorder. We must see their role to be that of educating service providers about what they have learned. In effect, they are "citizen scientist" who share authoritative knowledge with service providers and expect to be partners in decisions affecting their children. **The new role of parents, patients and practitioners as "learning advisers" (and the skills needed to fulfil this) have been promoted through this Project.**

Although specific treatments for neuromuscular diseases (NMD) or DMD have not yet reached, the natural history of the disease and life quality can be changed by the targeting of interventions to known manifestations, complications, therapies, social and physical rehabilitation. *To reach these objectives it is necessary a multidisciplinary approach to caring for patients with NMD in which patient and family should actively engage with the medical professionals who coordinate clinical care. It is a crucial need to create the "multidisciplinary care" consisting of educational, social and healthcare specialists that includes the parents and patients which have to develop the individualized education, rehabilitation and health care programs.*

It is compulsory to operationalize the "family-centered care" philosophical constructs (e.g. families and professionals share decision making, professionals use a strengths-based approach when working with families) and use these constructs to critique and strengthen practices, programs, or policies that affect NMD population groups.

V. Contacts of the project partner institutions

UNIVERSITATEA DIN CRAIOVA, Romania

Webpage: <http://www.ucv.ro/>
http://cis01.central.ucv.ro/educatie_fizica-kineto/

Contact persons:

Eugenia Rosulescu, email: erosulescu@yahoo.com

Mihaela Zavaleanu, email: mihaela.efs@gmail.com

ASOCIATIA PARENT PROJECT, Romania

Webpage: www.parentproject.ro

Contact persons:

Isabela Tudorache, email: isatudo@yahoo.com

Doru Tudorache, email: ppromania@hotmail.com

FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS, Italy

Webpage: <http://www.fondazioneospedaliriuniti.it/>

Contact persons:

Roberto Penna, email: Roberto.Penna@ospedaliriuniti.marche.it

Elisa Marconi, email: elisa.marconi25@gmail.com

ACTION DUCHENNE LIMITED, United Kingdom

Webpage: <http://www.actionduchenne.org/>

Contact persons:

Kate Angus, email: kate@actionduchenne.org

Mary Down, email: home@marydown.go-plus.net

UNIVERSITY EDUCATIONAL CIRCLE, Latvia

Webpage: <http://educationgroup.ucoz.lv/>

Contact persons:

Mara Dirba, email: mara.dirba@gmail.com



UNIVERSITY OF CRAIOVA, ROMANIA

http://cis01.central.ucv.ro/educatie_fizica-kineto/



ASOCIATIA PARENT PROJECT, ROMANIA

www.parentproject.ro



FONDAZIONE OSPEDALI RIUNITI ANCONA ONLUS, ITALY

<http://www.fondazioneospedaliriuniti.it/>



UNIVERSITY EDUCATIONAL CIRCLE, LATVIA

<http://educationgroup.ucoz.lv/>



ACTION DUCHENNE LIMITED, UNITED KINGDOM

<http://www.actionduchenne.org/>

This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.