



**eamda**

40<sup>th</sup> Annual General Meeting  
Milan, September 16-18, 2010

**UILDM: Strength through Unity**



# The Italian Association for Muscular Dystrophy

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UILDM - Unione Italiana Lotta alla Distrofia Muscolare is the Italian Association for the fight against Muscular Dystrophy, founded in August 1961 with well-defined aims and projects:

- promoting and encouraging the social integration of people with disability
- promoting scientific research and health information on neuromuscular diseases

Today the Association is led by a Board of 13 voluntary members elected by a National Assembly composed of more than 400 commissioned associates who represent all our community (>13.000 in 2009)

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

## The local Branches

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The Association has 78 local Branches located throughout the national territory. Some of them have their own permanent staff, although most of the work is done by volunteers.

All local Branches carry out social work and provide people with Muscular Dystrophies, their families and social or medical operators with information on these diseases. Moreover, they are committed to awaken public opinion to disabled people's problems.

Some Branches carry out also medical assistance, rehabilitation and prevention services, in close collaboration with Universities and the Public Health Service.

# Against architectural barriers

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*Being able to move means knowing, living and growing*

*Essential requirements for a normal life*

It is almost impossible to separate UILDM from the fight against architectural barriers of any kind: in public transport and buildings, in meeting-places and recreational areas.

Nowadays, technology has made significant progresses and what looked like a dream a few years ago, with the right instruments it has become a reality even for severely physically disabled people.

## Against all barriers

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However, UILDM is convinced that integration comes first of all through the destruction of **cultural and psychological barriers**, which often cause rifts among people.

This is the reason why the Association has expanded throughout Italy by means of various Branches, some of which operate in difficult environments, such as in Central-Southern Regions, where you can still find cases of individuals being cut off from the rest of the society.

# The scientific research

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In the field of scientific research, a noteworthy boost was given by Telethon, the Marathon brought to Italy by UILDM in 1990 with the aim of collecting funds to finance scientific projects on Muscular Dystrophies.

In 1992, Telethon enlarged its areas of research in order to include the study of other illnesses of genetic origin, but UILDM still remains its utmost important partner.

# The Alliances

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Next year UILDM turns fifty.

During these years, it has always favoured Unity.

At the beginning, it was Unity among people with muscular dystrophies and their families.

Then, Unity with people affected by similar diseases (neuromuscular diseases patients' associations), expressing the same functional troubles and the same assistential needs.

Nowadays, we are supporting the idea that what is needed is Unity with all people with disabilities (federations) and also with all those who want to fight for patients rights (civic organizations).

# Alliances with NMD patients' associations

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The most important organizations UILDM established strong alliances with, are:

## In Italy

AISLA (*Italian ALS Association*)

ASAMSI and FamiglieSMA (*two Associations of parents whose children are affected by SMA*)

FIAN (*a network of Associations of people with Neurological Disorders*)

## Abroad

EAMDA

WANDA

# Alliances with disabled people' associations

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UILDM also actively adheres to several organizations committed to improve the quality of life of people with disabilities:

## In Italy

*FISH (umbrella organization gathering 32 Associations of people with disabilities and their families)*

*CND (National Council on Disability)*

## Abroad

*DPI (Disabled Peoples' International)*

# Alliances with civic organizations

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In Italy the most important civic organization UILDM has created an alliance with is **Cittadinanzattiva**, whose main objectives are:

- the promotion of civic participation
- the protection of citizens' rights in Italy and in Europe

Cittadinanzattiva considers citizens to be a fundamental resource for democracy who play an active role in society and should have the opportunity to participate in everyday policy-making.

Cittadinanzattiva's European Network is **Active Citizenship Network (ACN)**.



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# FIRST RESULTS

# NEMO Clinical Centre



Fondazione Serena



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# Same rights everywhere: in Italy

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# The Italian Council of Neuromuscular Diseases

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*February 2009:* a decree of the Ministry of Labour, Health and Welfare established the *Italian Council of Neuromuscular Diseases*

*March 2009:* the Council officially settled down at the General Directorate for Healthcare Planning, Basic Level of Care and Ethical System Principles

*Basic aims:*

1. providing not guidelines, but useful **information** for the development of appropriate and effective care pathways for all people with severe progressive neuromuscular diseases
2. assuring equal opportunities of care, regardless of the region where you're born or where you live



## The Members of the Council

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The Council consists of a large representation of Patients' Associations:

**AISLA** (*Italian Association of ALS*)

**AISM** (*Italian Multiple Sclerosis Association*)

**ASAMSI** (*Association for the Study of Spinal Muscular Atrophy*)

**FAIP** (*Italian Federation of Associations of Para-quadruplegics*)

**Famiglie SMA** (*association for Spinal Muscular Atrophy*)

**Parent Project** (*organization engaged with Duchenne Muscular Dystrophy*)

**FISH** (*Italian Federation for Overcoming Handicap*)

and members of the Ministry, representatives of the Regions and some of the highest "technical experts" in the field.



# The activities of the Council

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Starting from the critical aspects submitted by the Associations, the *Council* has identified five thematic areas, which later became the subject of **five working platform**:

1. Diagnosis and Certification
2. Care Pathway “Hospital-Territory”
3. Registries
4. Rehabilitation
5. Research

The five platforms seen the involvement of **technical experts** from many different disciplines, whose contribution was essential for proper “comprehensive care” of patients and families.

Then, not only neurologists and physiatrists, but also pneumologists, otorhinolaryngologists, phoniatic experts, epidemiologists.

And also: nurses, physiotherapists, speech therapists, psychologists, social workers.

A clear sign, this, that the **multidisciplinary approach** and the **integration** of medical, social and psychosocial interventions are requisites without which we will never manage to work satisfactorily.

# The results of the Council

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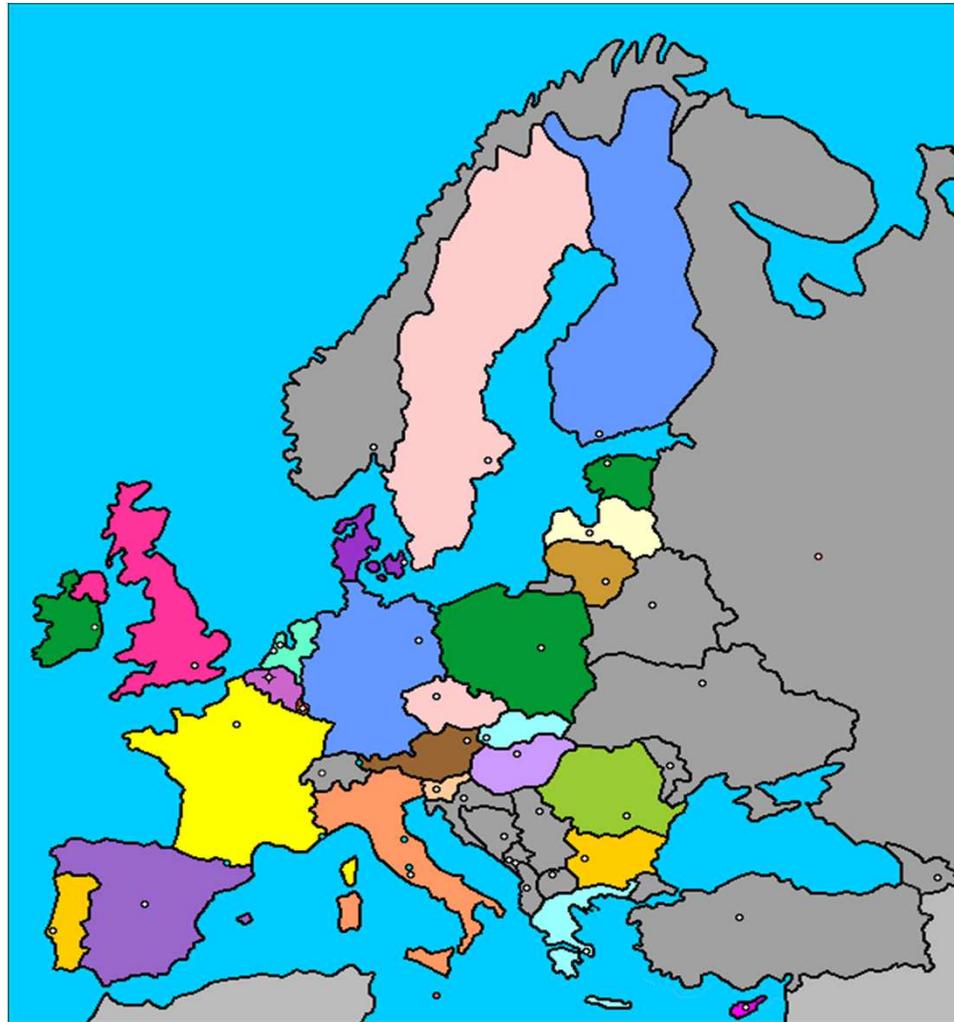


The result of this work was a **Report**, accompanied by several technical annexes, given to Health Minister last February who presented it to the Conference State-Regions. If the information contained in it were to become binding for Italian Regions, this could finally mark the turning-point in the care pathway that patients have been waiting for a long time.

Furthermore, the documentation produced by the platform working on *Rehabilitation* was officially presented as a "Recommendation" to the Ministerial Working Group on Drafting Guidelines in Rehabilitation, as well as the document prepared by the table on *Diagnosis and Certification* - concerning simplification and recognition of disability and handicap - was brought to the attention of INPS (National Institute for Social Security).

Finally, another important result was the possibility of a transformation of the *Council* into a **Permanent Observatory** for the monitoring and control, in order to guarantee **uniformity of treatment** on all national territory and, possibly, a **correct application** of the information provided.

# Same rights everywhere: in Europe



# Putting Citizens at the center of EU Health Policy

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*May 2010:* thanks to the alliance with ACN, UILDM was in the European Parliament in Brussels to discuss putting citizens in the centre of EU Health Policy together with over 100 representatives from other european patients' and civic associations and also members of European Parliament and of European Commissioner of Health and Consumer Affairs.

The event had 2 aims:

1. Presenting the project “Assessing patients Rights in Europe: a citizens’ approach”, that aims to assess the situation of 14 Rights as stated in the **European Charter of Patients’ Rights** in various European countries and consequently set up a report on the state of these rights.
2. Presenting a declaration for the institutionalization of the European patients’ Rights Day.

# The European Charter of Patients' Rights



The European Charter of Patients' Rights was drafted in 2002 by Active Citizenship Network in collaboration with **12 citizens' organizations** from different EU countries: Portugal, Italy, Spain, Denmark, Germany, Belgium, Austria, Greece, the Netherlands, United Kingdom, Ireland.

It states **14 patients' rights** that together aim to guarantee a "high level of human health protection" (Article 35 of the Charter of fundamental rights of the European Union) and to assure the high quality of services provided by the various national health services in Europe.

The 14 rights are an embodiment of fundamental rights and so they must be recognised and respected in every country. They are also correlated with **duties and responsibilities** that both citizens and health care stakeholders have to assume.

The Charter applies to **all individuals**, recognising the fact that differences, such as age, gender, religion, socio-economic status etc, may influence individual health care needs.



# The 14 patients' Rights

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1. Right to preventive measure
2. Right of access
3. Right to information
4. Right to consent
5. Right to free choice
6. Right to privacy and confidentiality
7. Right to respect of patients' time
8. Right to the observance of quality standards
9. Right to safety
10. Right to innovation
11. Right avoid unnecessary suffering and pain
12. Right to personalized treatment
13. Right to complain
14. Right to compensation

# Assessing Patients' Rights in Europe

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Using this Rights as starting point, ACN developed a set of **14 indicators** (one for each right) and a methodology for assessing patients' rights in Europe inspired by a Civic information (**civic audit**) approach, which has been used as a framework in the Italian experience of Cittadinanzattiva.

This report will:

1. produce information on the **actual situation of patients' rights**;
2. try to **change the conception of citizens** as passive and inactive into that of the idea of conceiving of them as active citizens involved in the production of information with the aim of participating in the improvement of services and the process of policymaking;
3. attempt to **facilitate the empowerment of citizens' organization** and citizens themselves in the protection of rights and the caring of common goods such as health.

**The final results** of the monitoring activity, contained in the report, will be presented during the 5th European Patients' Rights Day 18 April 2011 events in each country and at the European level.

# European Patients' Rights Day

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Putting Citizens at the center of Health Policy begins with guaranteeing patients rights are respected.

The reinforcement of Patients' rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country.

It is thus essential to increase awareness regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect.

ACN believes that celebrating a **European Patients' Rights Day every year** (18th April) in all EU Member States is greatly contributing to this goal.

It is common occasion to inform, discuss and take commitments to improve patients' rights in Europe and put citizens at the center of health policy.

# *Unity is strenght!*



*In Italy*



*Acrossboarder*



# Conclusion

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Health is a common good  
and so it has to be defended  
by everybody for everybody!

*Thank you!*