



# UILDM

**eamda**

41<sup>st</sup> Annual General Meeting  
Prague, September 8-11, 2011



## Home sweet home: an associative experience of independent living

Cira Solimene e Marco Rasconi

UNIONE ITALIANA LOTTA ALLA DISTROFIA MUSCOLARE  
NATIONAL HEADQUARTERS: VIA VERGERIO 19/2 - 35126 PADOVA TEL. +39 049 80 21 001  
BRANCH IN MILAN: VIA LAMPEDUSA 11/A - 20141 MILANO TEL. +39 02 848 00 276

### Organization



Until 1972, the headquarters of the association was in Trieste, then it was transferred in Padova, where it is located at present.

Today UILDM has 78 local branches some of which have their own permanent staff, although most of the work is done by volunteers; it 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 (>12.000 in 2010).

After 50 years, it keeps Milcovich's aims and projects.

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

3

### Health Information



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.

Nationwide, the information is guaranteed by the hard work of the **press and communication office**, the **information desk** (by telephone and e-mail), the **toll**, the **website**, the **magazine DM**.

A **medical committee**, composed of 9 members chosen among the best professionals in Italy on neuromuscular diseases, always supervises the information provided by properly trained operators.

5

### The Italian Association for Muscular Dystrophy



UILDM - Unione Italiana Lotta alla Distrofia Muscolare is the Italian Association for the fight against Muscular Dystrophy, founded in August 1961 by Federico Milcovich, a man with muscular dystrophy, living in Trieste whose aims and projects were:

1. Promoting **scientific research**, **health information** and **healthcare** in neuromuscular diseases
2. Promoting and encouraging the **social integration** of people with disabilities

2

### Scientific research



UILDM promotes scientific research especially supporting Telethon, the Marathon brought to Italy by UILDM itself 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 with more than 10 million euros collected so far to fund clinical trials.

4

### Healthcare



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

Nationwide, in 2007 UILDM realized in Milan the first NEMO Clinical Centre, a specialized centre of excellence dedicated to people with neuromuscular diseases, that provides a comfortable environment to patients and their families who can find in it a multidisciplinary care in one place.

By the end of 2011, another NEMO Centre will be created in the southern of Italy (Messina - Sicilia), so patients resident in the south of the country will be more easily able to reach it.

6

## RESEARCH AND ASSISTENCE ARE NOT ENOUGH!



UILDM was born in 1961 to fight against the muscular dystrophy.

But the disease is only the visible enemy.

The most difficult struggles that people with disabilities have to do every day are against invisible enemies: indifference, loneliness, exclusion, cultural barriers, bureaucracy, public immobility, and so on....

Only one struggle will defeat all this enemies: the fight for the protection of the rights of persons with disabilities.

Disabled people themselves must fight for their rights and this is possible only if they are informed about them.

We have a duty to do so.

7

## The information about rights



UILDM created in 1995 a Centre for legislative documentation whose objectives are the monitoring and analysis of the legislation about people with disabilities and their families and the production of specific information.

The main service, best-known even outside the association, is the website [www.handylex.org](http://www.handylex.org), one of the earliest sites on disability in Italy, which contains more than 500 rules.

The new laws are published on the site, but also sent to anyone who requests it. However, handyLex strenght lies not only in the daily work of observatory on the new regulations, but also in the direct contact with people asking questions (about 600 a month).

Overall, handyLex website has about 10.000 accesses a day.

8

## The conquest of rights



While we inform, fight and wait for the laws are applied, we also try to provide answers for the assertion of rights for disabled people.

Particularly, UILDM fully shares principles, values and contents of the **UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES** (2006).

The project "HOME SWEET HOME" can be considered an answer for the assertion of two specific rights stated in the articles 19 and 20 of the UN Convention: the right to independent living and the right to personal mobility.

9

## Right to independent living



### Article 19 - Living independently and being included in the community

*States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment of this right and their full inclusion and participation in the community, including by ensuring that:*  
*Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*  
*Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*  
*Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

10

## Right to personal mobility



### Article 20 - Personal mobility

*States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:*

*Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;*  
*Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;*  
*Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;*  
*Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.*

11

## Home sweet home



HSH is a project realized by UILDM branch in Milan, that was founded in 1968 and is one of our oldest and most active branches, in which the disabled members play a key role in promoting and coordinating personally the activities carried out by the Association, whose aims are especially to encourage growing, empowerment and awareness in people with disabilities.



12

## HSH: Aims



In Neuromuscular diseases the objective need of physical assistance establishes family ties based on physical dependence that too often becomes a psychological dependence and prevents the development of personal autonomy outside the family and "the capacity to manage themselves".

The aim of the project HSH is to provide people with muscular dystrophy tools to manage their life by actors starting from the management of personal assistance itself, up to the economic sustainability of their project of "independent living".

13

## Why «associative experience»



HSH wants to create an alternative to family life where people with muscular dystrophy try to live in autonomy, supported by the Association network, whose tasks are:

1. building a specific partnership that allows to find an «associative home» with automation tools at an affordable price;
2. identifying a suitable candidate based on: degree of personal maturity, family and living situation, economic sustainability (only for rent and food);
3. performing a detailed needs analysis;
4. developing and managing the necessary interventions, including personal assistance (that UILDM directly provides with the support of the municipality), monitoring them periodically until the person becomes completely independent also by the association.

14

## HSM: the steps



- 1) Developing the project and request funding to the municipality (Law n. 162/1998 on independent living)
- 2) Dissemination of the project through an effective communication campaign
- 3) Analysis of requests and choice of the candidate
- 4) Verification of requirements through several interviews with all the family supported by professionals (social workers, doctors, psychologists)
- 5) Weekly planning of assistance
- 6) Monitoring and weaning.

15

## HSM: weekly planning



	Lun	Mart	Mer	Giov	Ven	Sab	Dom	
00.00 - 06.00								
06.00 - 08.00	X	X	X	X	X			
08.00 - 10.00						X	X	
10.00 - 12.00						X	X	
12.00 - 14.00								
14.00 - 16.00								
16.00 - 18.00								
18.00 - 20.00	X	X	X	X	X			
20.00 - 22.00	X	X	X	X	X	X	X	
22.00 - 24.00	X	X	X	X	X	X	X	
<b>Tot. UILDM</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>6</b>	<b>6</b>	<b>22</b>
<b>Tot. Lavoratore Cooperativa</b>	6	6	6	6	6			30
<b>Tot. Volontariato Territoriale</b>						4	2	6
<b>TOTALE</b>	<b>8</b>	<b>8</b>	<b>8</b>	<b>8</b>	<b>8</b>	<b>10</b>	<b>8</b>	<b>58</b>

16

## HSM: the partnership



17

## Via Savona 127 - 2007



18

## Via Savona 127



19

## Via Melotti 2 (Rogoredo) - 2009



20

## Via Melotti 2 (Rogoredo)



21

## Via Mulas 4 - 2011



22

## Via Mulas 4



23



**Damn technology!  
Now I have to go somewhere!**

24