



Fondazione IRCCS Ca' Granda  
Ospedale Maggiore Policlinico

Sistema Socio Sanitario



Regione  
Lombardia



DIPARTIMENTO DI NEUROSCIENZE E DI SALUTE MENTALE  
U.O.: Neuropsichiatria dell'Infanzia e dell'Adolescenza - U.O.N.P.I.A  
Direttore: Dott.ssa Maria Antonella Costantino

SAPRE - Settore di Abilitazione Precoce dei Genitori  
Coordinatore: Chiara Mastella

SAPRE  
is pleased to invite you to



\*(From 18<sup>th</sup> June to 25<sup>th</sup> June "My kid's got wheelz", 9<sup>th</sup> annual, theoretical and practical summer training program)



SAPRE (roughly translated as the Service for the Early Empowerment of Parents), which is part of the Child and Adolescent Neuropsychiatry Unit of IRCCS Ca' Granda Foundation, Ospedale Maggiore Policlinico in Milan, is organising its 9<sup>th</sup> annual:

### "MIO FIGLIO HA UNA 4 RUOTE 2017" (2017 MY KID'S GOT WHEELZ)

A residential, theoretical and practical training program to support and train all parents who have to face their child's world, who is affected by a neuromuscular disease, and who is able to autonomously operate an **electric or manual wheelchair**.

It is open to mothers, fathers, siblings, grandparents, friends, operators and whoever would like to participate. Everybody will learn, sitting in a wheelchair right next to their child and together with the many other participants, how to operate it and to discover all the advantages and disadvantages related to controlling the wheelchair and its transportation.

Children will improve their ability to use the wheelchair by learning to play with others and by challenging themselves to face their own limits. In particular, they will be able to enjoy themselves naturally.

I have fun..., I go to the beach..., I play with my friends and with my siblings. My parents are relaxed because there's somebody who looks after us...while they learn and exchange ideas and everyday life experiences with other parents!



By operating a wheelchair, both at home or out on the street, you will learn rules and tricks to get around safely, to protect yourself and others, as well as your wheelchair. Everyone will realize first-hand what it is like to live in a wheelchair and still be able to play, explore, learn, dance, sing and make new friends.

**What to expect? Find out by watching this video of the previous program 2016:**

MF4R 2016 - <https://youtu.be/fv-4nOXhYpA>

MF4R 2015 - <https://youtu.be/MT4dfSL2GcA>

MF4R 2013 - <http://www.youtube.com/watch?v=rVCWza4loBo>





## TRAINING PROGRAM GOALS:

We want to show you that you can:

- **"get to know"** the wheelchair from all its interesting or curious perspectives and not see just as a limitation because your child cannot walk
- **"accept"** the wheelchair when the dream that your child will grow up and ride a bike collides with the reality of having a disability
- **"teach"** by sharing their point of view to those who have to care for children in a wheelchair
- **"play"** despite the difficulties of the disease
- **"learn"** by sharing experiences

## THE PROGRAM OFFERS THE CHILDREN'S FAMILIES THE OPPORTUNITY TO:

- spend enjoyable time in a friendly environment
- get to know each other by making new friendships and renewing old ones made in previous years
- facilitate meeting other children with equal status
- facilitate meeting other parents
- help find strength and encouragement
- share experiences and advice/information on useful topics: breathing, physiotherapy, psychology, practical everyday life
- review emergency procedures for those who need it and try to answer your unanswered questions...

## MY KID'S GOT WHEELZ: WHO IS IT FOR?

Families (mothers, fathers, siblings, grandparents), friends and operators with children affected by a neuromuscular disease (SMA 1, SMA 2, SMA 3, muscular dystrophy and similar) who are able to operate an electric or manual wheelchair.

In addition, this year we will be dividing the children into groups:

**Baby** (kindergarten), **Minion**, **Junior** (elementary school), **Superstar** (teenagers).

Our SAPRE-trained STAFF will look after your children while you attend the parent workshops. They are a group of child care workers consisting of instructors, entertainers and trained technical and health staff.

## MY KID'S GOT WHEELZ: HOW AND WHEN?

From Sunday, 18/06/17 to Sunday, 25/06/17





## MY KID'S GOT WHEELZ: WHERE?

It is located right by the SEASIDE in Lignano Sabbiadoro (UD).

The village has direct access to the beach, it is surrounded by 80 hectares of pine forest crossed by roads and trails: it offers a peaceful environment, the fragrant scent of pine trees and sea air, a crystal clear sea where all barriers have been removed so the children can test their skills in a wheelchair while in close contact with nature.

For more information: <http://www.getur.com/seaside?b=village>

## MY KID'S GOT WHEELZ: HOW MUCH DOES IT COST?

Registration fees cover the cost of a one-week stay (7 nights) and include accommodation, breakfast, lunch, dinner (from dinner on day of arrival to lunch on day of departure). The Training program is free.

- Children up to 4 years old - FREE
- Children with SMA - FREE
- Children between 4 to 12 years old - €170
- Over 12 years old - €310

Included in the price for each room: 1 beach umbrella, 1 lounge chair and 1 beach chair on the private beach which is just a few metres from the "Alle Vele" facility which will be hosting us.

**Registration is open until all rooms are sold out.**

**To register for the Training program you MUST:**

- Fill out the attached form and return it by e-mail to [bellashakhmirza@gmail.com](mailto:bellashakhmirza@gmail.com) or [katjuscia.marconi@policlinico.mi.it](mailto:katjuscia.marconi@policlinico.mi.it) or by fax 02/501164. As you can see, it is very simple, you just have to provide your personal information (number of family members per room). In the section "type of room request", place an X in the box to select the type of room you need (double, triple, quadruple, etc.).
- Pay the confirmation deposit by 15th March 2017 which is:
  - ✓ €100 - for adults over 12 years old
  - ✓ €50 - for children from 4 to 12 years old
- Full payment of the registration fee must be made no later than 24th May 2017.
- Payment procedure will be provided upon registration.
- For safety reasons all participants must have a civil liability insurance policy . In particular, children in electric wheelchairs must obtain an "extension" of the policy expressly covering your child's electric wheelchair, otherwise you will not be covered for any damage that may be caused during its operation.







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We hope to have the pleasure to host you here in Italy and to share this new learning and life experience with you!

For further information, do not hesitate to contact us: Organization secretary -  
Katjuscia Marconi - Cell. 347/5173159 or Bella Shakhmirza Cell. 338/4005428 - email:  
[bellashakhmirza@gmail.com](mailto:bellashakhmirza@gmail.com) or [katjuscia.marconi@policlinico.mi.it](mailto:katjuscia.marconi@policlinico.mi.it).

Best Wishes from the SAPRE STAFF

Chiara Mastella (coordinator)

Unità Operativa di Neuropsichiatria dell'Infanzia e dell'Adolescenza

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Settoe  
Abilitazione Precoce  
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