



Duchenne  
**Parent  
Project**  
aps

# Together we are the future

## Insieme siamo futuro

### 20th International Conference on Duchenne and Becker Muscular Dystrophy

### XX Conferenza Internazionale sulla distrofia muscolare di Duchenne e Becker



## FRIDAY FEBRUARY 17

14:00

### Registration

15:00

### Parent Project meets the new families

*Ezio Magnano - Ilaria Zito - Emanuela Giullitti - Tiziana D'Auria  
- Cristina Bella, Parent Project aps*

17:00

### PARALLEL SESSIONS (Italian only):

- **I'm here too. Being a sibling of a DMD/BMD patient**  
*Marica Pugliese, Parent Project aps*  
*Laura Gentile, Omar*  
*Bianca Ragona - Giacomo Buccella, Parent Project aps*
- **What we eat matters. Nutritional aspects in DMD and BMD**  
*Simona Bertoli, Università degli Studi di Milano*
- **When complexity increases. DMD/BMD and related issues**  
*Paolo Alfieri - Francesca Cumbo, Ospedale Pediatrico Bambino Gesù, Rome*
- **Integrating and learning: school integration**  
*Giancarlo Onger, Coordinamento Nazionale Insegnanti Sostegno*
- **School devices and technology**  
*Fabrizio Corradi - Istituto "Leonarda Vaccari"*



20:30

### Dinner

# SATURDAY FEBRUARY 18

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## PLENARY SESSION

8:45

### A SPECIAL WELCOME

9:30

### ROUND TABLE

#### Taking caregivers at heart

This round table talks about the experience of being a caregiver, emphasizing the bureaucratic, psychosocial and experiential aspects, through the intervention of experts and direct testimonies.

*Tiziana D'Auria - Parent Project aps*

*Carlo Giacobini - Società Cooperativa sociale Esplicando*

*Giada Perinel - Parent Project aps*

**Testimonies from families:** *Jacopo Verardo - Daniela Gallo - Alberto Di Grazia - Cettina Ali*

11:00

### Presentation of the European "Renoir" project

*Silvia Brunelli - Università degli Studi Milan- Bicocca*

11:10

### Coffee break



11:30

### SCIENTIFIC SESSION:

#### Improving muscle health, opposing inflammation and fibrosis

*Gloria Antonini - Parent Project aps*

*Michela Catteruccia - Ospedale Pediatrico*

*Bambino Gesù, Rome*

*Emilio Albamonte - Centro Clinico NeMO, Milan*

#### Q&A with:

Italfarmaco,  
Edgewise  
Therapeutics,  
Cumberland,  
Antisense  
Therapeutics,

• *M. Guglieri - FOR  
DMD Study,  
Santhera  
Pharmaceuticals,  
Fibrogen  
Capricor*

13:00

### LUNCH BREAK



## PARALLEL SESSION

### PARALLEL SESSION (Italian only):

#### The path of preimplantation genetic diagnosis when planning a pregnancy for carriers

*Emanuela Giulitti - Parent Project aps*

*Ilaria Zito - Parent Project aps*

*Daniela Zuccarello - University Hospital of Padua, PGT Italiano Network (N.I.D.O.)*

*Andrea Gallinelli - AUSL of Ferrara*

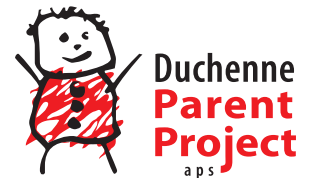
*Marina Forte - IVI, Rome*

### POSTER SESSION



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## PLENARY SESSION

14:00

### SCIENTIFIC SESSION:

#### Dystrophin restoration: mutation-specific strategies

*Ilaria Zito - Parent Project aps*

*Alessandra Ferlini - Ospedale Universitario  
Sant'Anna, Ferrara*

*Marika Pane - Centro Clinico NeMO, Rome*

#### Q&A with:

Sarepta  
Therapeutics,  
Wave Lifesciences,  
BioMarin  
Pharmaceutical,

Dyne Therapeutics,  
Avidity Biosciences,  
PepGen,  
*M. Pane for  
NS-Pharma*

15:30

### Presentation of the European "Grow-DMD" project

*Isabella Moroni - Istituto Neurologico C.  
Besta, Milan*

15:40

### Coffee break



16:00

### ROUND TABLE

#### The rehabilitation path, from diagnosis to adulthood

This round table addresses the topic of the rehabilitation process from the beginning of the project, through its construction and in the subsequent steps of the pathology, analyzing the different rehabilitation approaches through the intervention of technicians and direct testimonies

*Emanuela Giulitti - Parent Project aps*

*Anna Lia Frongia - UILDM, Rome and Policlinico Gemelli, Rome*

*Lavinia Fanelli - Policlinico Gemelli, Rome*

*Cristina Bella - Parent Project aps*

*Lucia Borgna - Oplà, Rome*

*Francesca Cumbo - Ospedale Pediatrico Bambino Gesù, Rome*

**Testimonies from families:** *Daniela Argilli - Maria Carmela Campana*

## PARALLEL SESSION

### SCIENTIFIC SESSION:

#### Clinical trials in Becker muscular dystrophy

*Fernanda De Angelis - Parent Project aps*

*Claudio Bruno - Istituto G. Gaslini, Genoa*

#### Q&A with:

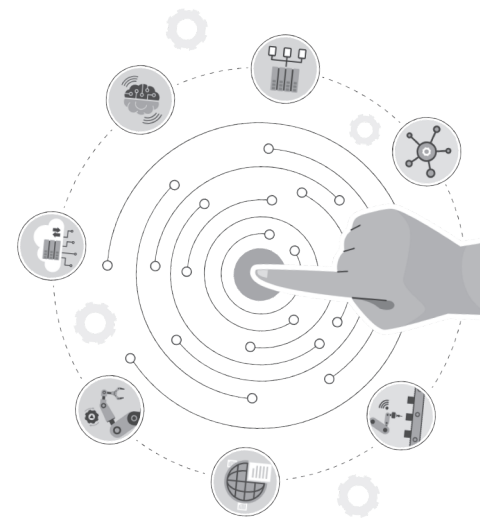
*L. Bello for  
ReveraGen &  
Santhera*

Edgewise  
Therapeutics,  
Italfarmaco

#### Emergency card in Becker muscular dystrophy

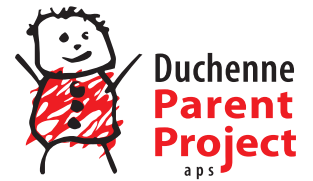
*Fabrizio Racca - Ospedale SS. Antonio e  
Biagio e Cesare Arrigo, Alessandria*

#### Q&A



# SATURDAY FEBRUARY 18

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## PLENARY SESSION

## PARALLEL SESSION

17:30

### ROUND TABLE

#### **Affectivity and sexuality: comparing two worlds**

*Pat Moeschel - Parent Project Muscular Dystrophy*

18:00

### CLINICAL SESSION

#### **Preventing and managing the emergencies in Duchenne/Becker**

*Filippo Buccella - Parent Project aps*

#### **Emergencies and steroids:**

*Luca Bello - Ospedale Universitario of Padua*

#### **Emergencies in fractures:**

*Maria Grazia D'Angelo - IRCCS E. Medea Bosisio-Parini, Lecco*

#### **Cardiac emergencies:**

*Rachele Adorisio - Ospedale Pediatrico Bambino Gesù, Rome*

#### **Respiratory emergencies and EC:**

*Fabrizio Racca - Ospedale SS. Antonio e Biagio e Cesare Arrigo, Alessandria*

#### **Projects of telecardiology and cardiorespiratory management:**

*Angelo Villano - Policlinico Gemelli, Rome*

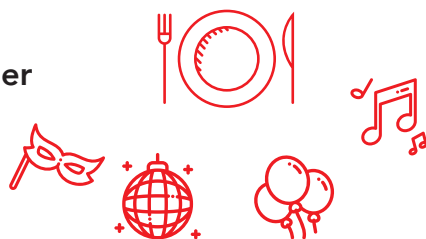
#### **Q&A**

19:30

### Poster awards

20:30

### Dinner



### PARALLEL SESSION

#### **Discussion group on the theme of affectivity and sexuality (open to young adult patients only)**

*Pat Moeschel - Parent Project Muscular Dystrophy*

**INSIEME SIAMO FUTURO**  
**TOGETHER WE ARE THE FUTURE**



# SUNDAY FEBRUARY 19

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## PLENARY SESSION

8:45

### OPENING

9:00

### SCIENTIFIC SESSION:

#### Gene Therapy in Duchenne muscular dystrophy

*Fernanda De Angelis - Parent Project aps*  
*Eugenio Mercuri - Policlinico Gemelli, Rome*  
*Giacomo Comi - Policlinico of Milan*

#### Q&A with:

Pfizer,  
Solid Biosciences, Roche,  
RegenXbio

10:30

### ROUND TABLE

#### Clinical trials: a conscious participation between doubts and opportunities

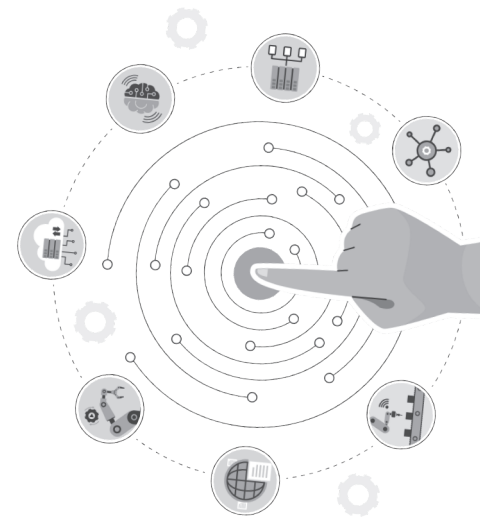
This session aims at addressing the aspects that most characterize the choice to participate in a clinical trial. Different points of view will be explored with the different actors involved.

*Marica Pugliese - Parent Project aps*  
*Marika Pane - Centro Clinico NeMO, Rome*  
*Francesca Magri - Policlinico of Milan*  
*Anna Petruzza - Parent Project aps*  
*Testimonies from families*  
**Testimonies from families:** *Alberto Bottaro - Debora Grandinetti - Matteo Tosetti*

12:00

### Lunch box

## PARALLEL SESSION



### PARALLEL SESSION (Italian only)

#### Laws, rights and bureaucracy

*Carlo Giacobini - Società Cooperativa sociale Esplicando*

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## PLENARY SESSION

## PARALLEL SESSION

13:00

### SCIENTIFIC SESSION

#### Strategies in preclinical phase: opportunities and considerations

*Annemieke Aartsma-Rus - Leiden  
University*

**Q&A**

12:30

### PARALLEL SESSION

#### Sports and disability

*Valeria Catarraso - Parent Project aps*

*Carmenrocca Sileo - Parent Project aps*

*Vincenzo Santucci - Consigliere Federale  
della FIB (Federazione Italiana Bocce)*

*Nino Diana - ASH Baskin Taranto*

*Affiliazione con CSI centro sportivo Italiano*

*Francesco G. Manfredi - Neuro Ortopedia*

*Ospedale Giovanni XXIII Bari*

*Melchiorre Ragona - ASD Albalonga*

*Wheelchair Hockey*

**Testimonies from families:** *Samuele*

*Ragona - Luca Montevicchi - Gabriele*

*Zendron - Stefano Dorgia*

14:00

**CLOSE**



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Parent  
Project**  
a.p.s.

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# 20th INTERNATIONAL CONFERENCE ON DUCHENNE AND BECKER MUSCULAR DYSTROPHY

17 - 19 February 2023 - Ergife Palace Hotel - Rome, Italy

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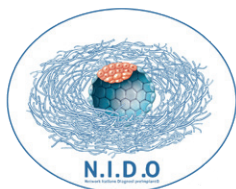
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