

Respiratory

Assessment and Management



Duchenne
Parent
Project
aps

Parent
Project
Muscular
Dystrophy **30**

of Duchenne Muscular Dystrophy:

*Current Standards
and Future Directions*

Rome, Italy,
September 25-27, 2024
Hotel NH Collection
Roma Giustiniano
Sala Giulio Cesare

WEDNESDAY 25 SEPTEMBER

06:00 pm-08:00 pm

Arrival and welcome cocktail

THURSDAY 26 SEPTEMBER

8:30 am-9:00 am

Welcome & introduction

Jodi Wolff, Filippo Buccella

Part 1 - Diagnostics:

9:00 am - 9:20 am:

Routine assessment of pulmonary function

Dr. Finder (Lecture 1)

9:20 am-9:40 am

Sleep assessment of breathing during sleep

Dr. Crescimanno (Lecture 2)

9:40 am-10:20 am

Group Discussion: *What are the standards of care for **current respiratory diagnostics** in different centers? What factors and challenges determine the standard of care at your institution (resources, equipment, geography, funding)? How might the current standards of care change in the future?*

10:20 am-10:50 am

COFFEE BREAK

Part 2 - Therapeutics (Chronic):

10:50 am-11:10 am

Airway Clearance

Dr. Chatwin (Lecture 3)

11:10 am-11:30 am

Chronic Nocturnal Ventilation

Dr. Amaddeo (Lecture 4)

11:30 am-11:50 am

Chronic Daytime Ventilation

Dr. Vianello (Lecture 5)

11:50 am-12:30 pm

Group Discussion: *What are the standards of care for **chronic respiratory therapeutics** in different centers? What factors and challenges determine the standard of care in your institution (resources, equipment, geography, funding)? How might the current standards of care change in the future?*

12:30 pm-1:30 pm

BUFFET LUNCH

Part 3 - Respiratory Aspects of New DMD Therapies:

1:30 pm-1:50 pm

New Therapies for DMD

Dr. Mercuri (Lecture 6)

1:50 pm-2:10 pm

Regulation: The Accelerated Pathway

Drs. Birnkrant and Katz (Lecture 7)

2:10 pm-2:30 pm

Methodology: Threshold FVC levels, Historical Controls and the Canadian Neuromuscular Data Registry (CNDR)

Drs. Katz and Birnkrant (Lecture 8)

2:30 pm-2:50 pm

Methodology: FVC % predicted versus Rideau Plots

Drs. Sheehan and Birnkrant (Lecture 9)

2:50 pm-3:20 pm

COFFEE BREAK

3:20 pm - 3:40 pm

Methodology: Outcome Proposals Based on Rideau Plots

Drs. Birnkrant, Katz and Sheenan (Lecture 10)

3:40 pm - 4:00 pm

Methodology: The Need for Cardiac Outcome Measures

Dr. Birnkrant (Lecture 11)

4:00 pm - 4:20 pm

The Status Quo: Case Studies and Conclusions

Drs. Katz, Sheehan and Birnkrant (Lecture 12)

4:20 pm-5:00 am

Group Discussion

The Evaluation of New Therapies: Do We Need a Change in Regulatory Approval Pathways and Study Methodologies?

5:45 pm - 8:30 pm

GUIDED TOUR

8:30 pm

DINNER

FRIDAY 27 SEPTEMBER

8:30 am-08:40 am

Considerations and remarks from

Day 1

Jodi Wolff, Filippo Buccella

Part 1 - Management of Procedures and Acute Respiratory Failure

8:40 am-9:00 am

Peri-Operative Management

Dr. Racca (Lecture 13)

9:00 am-9:20 am

Acute Respiratory Failure (Home Management)

Dr. Trucco (Lecture 14)

9:20 am-9:40 am

Acute Respiratory Failure (Hospital Management)

Dr. Racca (Lecture 15)

9:40 am-10:10 am

Group Discussion

What are the standards of care for assessment and management of perioperative situations, and acute respiratory failure? What factors and challenges determine the standard of care in your institution (resources, equipment, geography, funding)? How might the current standards of care change in the future?

10:10 am-10:40 am

COFFEE BREAK

Part 2- New Therapies and the Evolving Role of Patient Advocacy Organizations

10:40 am-11:00 am

Respiratory Issues from the Perspective of Patients, Patient Advocates, Families and Caregivers

Jodi Wolff, Filippo Buccella (Lecture 16)

Part 3- Closing remarks and Future Goals

11:00 am-12:30 pm

Wrap-up and open discussion: Lessons and Implications of the Meeting for different stakeholders

Jodi Wolff, Filippo Buccella, David Birnkrant, Sherri Katz

12:30 pm-1:30 pm:

BUFFET LUNCH

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