

Meeting Agenda (English Version) :

Saturday 28th March 2020

- 14.30-14.50 President greetings and summary of AIAF activities [S. Tobaldini]
- 14.50-15.00 Presentation of the new Scientific Committee 2020-2022 [F.Pieruzzi]
- 15.00-15.20 The Lyso-GB3 AIAF financed project: preview of the final results [R. Mignani]
- 15.20-15.40 Secondary cellular mechanisms triggered by storage accumulation in lysosomal diseases [G. Parenti]
- 15.45-16.30 Two parallel groups
- Group 1
- ANDERSON-FABRY DISEASE: DIAGNOSIS, SYMPTOMS AND GENTIC ISSUES
- [I.Tanini, A. Morrone, I. Romani, F. Pieruzzi]
- Group 2
- THERAPEUTIC OPTIONS: SPECIFIC TREATMENTS AND ADJUNCTIVE THERAPIES MANAGEMENT
- [M. Pieroni, G. Parenti, R. Mignani]

16.30-16.50 Coffee Break

- 16.50-17.35 Two parallel groups
- Group 1
- THERAPEUTIC OPTIONS: SPECIFIC TREATMENTS AND ADJUNCTIVE THERAPIES MANAGEMENT
- [M. Pieroni, G. Parenti, R. Mignani, F. Pieruzzi]
- Group 2
- ANDERSON-FABRY DISEASE: DIAGNOSIS, SYMPTOMS AND GENTIC ISSUES
- [I.Tanini, A. Morrone, I. Romani]

- 17.40-18.00 Wrap up of the group workshops and updating
- 18.00- 18.20 Rare disease patient rights and regulatory reference standards [R.Venturi]
- 18.20-18.30 Participants questions
- 18.30 Closing remarks

Sunday 29th March 2020

- 9.00 President greetings and summary of the daily activities [S. Tobaldini]
- 9.05 Fabry Disease in Poland [W. Nadolski]
- 9.20 Health Coaching practices for AIAF patients and caregivers [AIHC, Italian Health Coaching Association]
- 9.30 Group activities:

-The paradigms of malaise: When thoughts become limiting beliefs. How to transform limiting beliefs and expand wellness spaces [F. Di Coste]

- Illness: from unwanted guest to travel companion [A. Dargenio]

-Let's get creative: emotional expressiveness to overcome malaise [G. Salituri]

-Let's choose a healthy lifestyle: balanced nutrition and holistic well-being [C. Miletta Cossa]

12.30 Conclusions [S. Tobaldini]