II° European Symposium on Rare and genetic Cardiovasculas Diseases

The Patient's clinical pathway in inherited and rare disease: a journey toward precision medicine

➥ *Organizing & Logistic Secretariat*	SUMMEET SRL – ID 604
➥*Dates:*	05th – 06th -07th December 2023
➥*Venue*:	***Hotel Royal Continental*** *Via Partenope 38/44* *80121 - Napoli*
➥*Type*:	*In presence*
➥*Objective*:	*Provide an update to learners on emerging topics, acquire theoretical and practical knowledge on recent innovations, motivate the patient to continue with the therapy and make him aware of the high risk involved in not continuing or starting it*
➥*Scientific Coordinators:*	***Perry M. Elliott*** ***G. Limongelli***
➥*Participants:*	N. 120 Participants (Categories: Cardiology, Endocrinology, Metabolic Diseases and Diabetology, Internal Medicine, General Medicine)
➥*Duration (H/Days)*:	N° 3 Days

RAZIONALE SCIENTIFICO

On behalf of the Scientific Committee it is a great pleasure to welcome you to the city of Naples for the xth International Meeting on Inherited and Rare Cardiovascular Disorders, 2023.

Inherited and rare cardiovascular diseases comprise a group of more than 50 diseases, including primary arrhythmia disorders, malformation syndromes, cardiomyopathies, connective tissue disorders, congenital heart defects and metabolic diseases. Taken together, these disorders may affect up to 1 in 240 individuals and are a significant burden on healthcare services.

For much of the history of medicine, patients suffering from rare diseases have found themselves to be beyond hope, but in recent years, disease awareness has spread around the world and the advances in molecular genomics have facilitated personalised therapeutic managehat of patients with rare and ultra-rare disorders according to their specific phenotype.

The importance of rare cardiovascular disorders is reflected by recent efforts of national healthcare agencies to reduce diagnostic delay among patients with rare diseases, through the institution of disease-specific

"patient pathways". Fundamental to this effort is a multidisciplinary and collaborative approach between healthcare agencies, hospitals and healthcare providers.

The aim of this meeting is to improve the education of cardiologists and other specialists in the field of rare and genetic diseases and to highlight recent advances in inherited cardiovascular disease, with a particular focus on new approaches to diagnosis and management.

We are enormously fortunate to have some of the World's greatest experts in our faculty and sincerely wish you a successful and enjoyable meeting.

SCIENTIFIC PROGRAMME
Day One – 05 december 2023

8.30 Meeting Opening: European, National & Regional Key Figures.

Introduction and Greeting from the Authorities (Sindaco/Regione/Università/Commissione Europea/Ministero Salute/Istituzioni)

9.50 Introduction to Round Tables.
Giuseppe Limongelli - Perry Elliott

10.00 Round Table I. European, National & Regional Rare Disease Landscape. Where are we now? Where are we going?
Chairman Giuseppe Limongelli – Perry Elliott

The role of European parliament: ***Stelios Kympouropoulos*** (MEP)
The role of ERN: ***Maurizio Scarpa*** (MetabERN) – ***Arthur Wilde*** (Guard Heart ERN); ***Luca Sangiorgi*** (ERN Bone)
The role of EMA: ***Annalisa Capuano*** (EMA-AIFA)
The role of new technologies in rare diseases: ***Leandro Pecchia*** (President of the European Alliance for Biomedical Engineering and Science (EAMBES)
The role of patients association: ***Simona Belligambi/Annalisa Scopinaro*** (EURORDIS/UNIAMO)

11.30 Coffe Break

12.00 Lecture: Sudden Cardiac Death - ***Arthur Wilde***
Introduction: ***Cristina Basso***

12.30 Round Table. A law for sudden death in Italy.
Introduction: ***Pasquale Perrone Filardi - Ciro Indolfi - Vito De Filippo - Paolo Siani***

Participants: ***Marco Lacarra, Paolo Siani, Annalisa Scopinaro, Ilaria Francaleoni Bartali (Presidente OMAR), Francesco Macchia (OSSFOR), Giuseppe Limongelli - Cristina Basso - Camillo Autore - Marco Canepa - Ruth Biller***

13:15 Testimonianza - ***Ruth Biller***

13.30 Testimonianza: Come d'Aria – ***Alfredo Favi [oppure Maurizio De Giovanni]***

13.45 Conclusion & Lunch

INTERNATIONAL CARDIOMYOPATHY NETWORK–LAUNCH OF POLICY MANIFESTO

16.00 Introduction
Perry Elliott

16.10 Why do we need a strategy?
Iacopo Olivotto

16.40 Raising the patient voice
Joel Rose

17.10 The need for multidisciplinary Networks
Aris Anastasakis

17.40 Bridging the gap between science and clinical cardiology
Eloisa Arbustini

18.10 ICoN: The Agenda for Change
Perry Elliott

18.40 Conclusion

SCIENTIFIC PROGRAMME
Day two - 06 december 2023

8.00 Registration

8.45 Welcome and opening remarks
Chairs: Perry Elliot, Giuseppe Limongelli

SESSION ONE: HEART MUSCLE DISEASE

NEW GUIDELINES FOR CARDIOMYOPATHIES
Chairs: Giuseppe Limongelli, Perry Elliott

9.00 How the new Guidelines will change diagnosis and practice in CMPs?
J. Kaski

9.20 How the new Guidelines will change the approach towards risk assessment?
Elena Arbelo

9.40 Time for a molecular classification
E. Arbustini

HYPERTROPHIC CARDIOMYOPATHY
Chairs: F. Cecchi, Ruxandra Jurkut

10.00 Risk stratification in HCM: Not just sudden death
G. Gimeno

10.15 Managing LVOTO: from surgery to myosin inhibitors
I. Olivotto

10.30 Heart failure: the new frontier in HCM
E. Biagini

10.45 Discussion Coordinator
M. Losi, Maria Beatrice Musumeci

11.00 Coffee break

DILATED CARDIOMYOPATHY

Chairs: ***G. Sinagra, Philippe Charron***

11.30 Genotype and phenotype in DCM: From one to many diseases
Philippe Charron

11.45 Non dilated hypokinetc cardiomyopathy: putting the name in the context
M. Merlo

12.00 The future of precision medicine in dilated cardiomyopathy
Pablo Garcia Pavia

12.15 Discussion Coordinator
A. D'Andrea, Viviana Maestrini

ARRHYTHMOGENIC RIGHT VENTRICULAR CARDIOMYOPATHY

Chairs: ***Aris Anastasakis, A. Tsatsopoulou***

12.30 Correlating genotypes with disease: clinical & molecular classification of ARVC
A. Protonotarios

12.45 The impact of multimodality imaging on the diagnosis of ACM
B. Bauce

13.00 Advances in risk assessment and the management of ventricular arrhythmias
Andrea Mazzanti

13.15 Discussion Coordinator
Gerardo Nigro, Berardo Sarubbi

13.30 Lunch

MYOCARDITIS AND INFLAMMATORY DISEASES

Chairs: ***Aris Anastasakis, Massimo Imazio***

14.30 When to perform genetic testing in myocarditis?
S. Klaassen

14.45 When to perform endomyocardial biopsy in myocarditis?

A. Caforio

15.00 Diagnosis and management of cardiac sarcoidosis
Enrico Ammirati

15.15 Discussion Coordinator
Cristina Chimenti, M. Pieroni

STORAGE, INFILTRATIVE, NEUROMUSCULAR DISORDERS
Chairs: ***Michele Emdin, E. Arbustini***

15.30 Cardiac Amyloidosis: diagnosis and natural history
Michele Emdin

15.45 Fabry Disease: the importance of registries and networks
M. Pieroni

16.00 Neuromuscular Disease and the Heart
K. Wahbi

16.15 Discussion Coordinator
Vincenzo Russo e Francesca Graziani

16.30 Coffee break

PAEDIATRIC HEART FAILURE & CARDIOMYOPATHIES
Chairs: ***S. Favilli, M. G. Russo***

17.00 Etiology and clinical presentation in children
G. Limongelli

17.15 Risk prediction of outcome in children with Cardiomyopathies
Gabrielle Norrish

17.30 Novel therapeutic approaches in childhood heart failure and Cardiomyopathies
Cordula Wolf

17.45 Discussion Coordinator
Michele D'Alto, Giuseppe Pacileo

18.15 Conclusions

SCIENTIFIC PROGRAMME
Day Three - 07 december 2023

8.30 Introduction
Giuseppe Limongelli

8.35 Lecture: What is a cardiomyopathy in 2023?
Perry Elliot

SESSION TWO: GENE THERAPY

9.00 Video
John Crowley

GENE THERAPY IN RARE DISEASES
Chairs: ***Lucie Carrier, Gaetano De Ferrari***

9.15 New Therapeutic approaches for transthyretin cardiac amyloidosis
Francesco Cappelli

9.30 Gene Therapy in muscular dystrophies
Vincenzo Nigro

9.45 Gene Therapy for Ion Channel Disease
Lia Crotti

10.00 New therapeutic approaches for Cardiomyopathies
Sharlene Day

10.15 Discussion Coordinator
G. Frisso, Giancarlo Parenti

SESSIONE THREE: FUTURE RESEARCHERS

New FRONTIERS in INHERITED, CONGENITAL AND RARE DISEASE RESEARCH
Chairs: ***Francesco Loffredo, Giovanni Di Salvo***

10.30 Murcia Team (Spain)

10.45 London Team (UK)
Douglas Cannie (*no accreditamento*)

11.00 Naples Team (Italy)
Monda Emanuele (*no accreditamento*)

11.15 Athens Team (Greece)

11.30 Discussione Coordinator
Giuseppe Palmiero, Franscesca Graziani

11.45 Coffee break

SESSIONE FOUR: HEART RHYTHM

MOLECULAR AUTOPSY & FAMILY SCREENING IN SUDDEN ADULT DEATH SYNDROME
Chairs: ***Giuseppe Limongelli, Gaetano De Ferrari***

12.15 Sudden cardiac death prevention: a public health priority
Ruth Biller

12.30 The emerging role of molecular autopsy
Cristina Basso

12.45 How to identify and manage family members at risk?
Aris Anastasakis

13.00 Discussion Coordinator
B. Bauce, Marco Canepa

13.30 Lunch

SESSIONE FIVE: VESSELS

FAMILIAL DYSLIPIDAEMIAS

Chairs: ***Paolo Calabrò, Maria Donata Di Taranto***

14.30 Familiar hypercholesterolaemia: diagnosis and management
Maurizio Averna

14.45 Familiar dysbetalipoproteinaemia: diagnosis and management
Marcello Arca

15.00 Genetic causes of hypertriglyceridemia: diagnosis and management
Alberto Zambon

15.15 Discussion Coordinator
Giovanni Cimmino, Francesco Natale

15.30 Coffee Break

GENETIC AORTOPATHIES

Chairs: ***E. Bossone, M. De Feo***

16.00 Marfan syndrome and inherited aortopathies
Bart Loeys

16.15 Non-syndromic aortopathies
Arturo Evangelista

16.30 Genetics in bicuspid aortic valve
Alessandro Della Corte

16.45 Discussion Coordinator
Betty Giusti, Guglielmina Pepe

17.15 Conclusions & Final Remarks