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Eamas is a non-profit patient's association, operating since 1998, enhancing and promoting the relationships between researchers, doctors, specialists, patients and families. We aim to **improve the assistance to people, and their families, having rare diseases**. We were born from the need to address, support and be accountable when holding a rare condition. A disease is defined rare when occurs in five people every 10,000 inhabitants. Millions of people in Italy, tens of millions in Europe and worldwide are involved by rare conditions. **We believe that the experience of those who suffer and those who help should be further enhanced to promote education and care**. We aim to promote research and rise resources in order to **improve the quality of life of patients and their families**. Eamas is in collaboration with other Italian, European and world wide patient's groups sharing the interest to develop basic research, new drugs discovery, new therapies, aimed to improve care and support for people having rare conditions. **Our goal is to disseminate a culture of aggregation between all players and stake holders** in order to sponsor adequate answers that a rare condition like Fibrous Dysplasia and MAS still require.

SPONSORSHIP

Società Italiana di Endocrinologia e
Diabetologia Pediatrica
Via San Francesco da Paola, 37 - Torino



SPONSORSHIP REQUESTED



We thank all those who gave and make their own contribution to the realization of the event.

Fibrous dysplasia and Mc Cune-Albright Syndrome Transition to adult age

VII Eamas Conference Saturday 18 March 2017

CENTRO CHIRURGICO TOSCANO
Via dei Lecci, 22, 52100 Arezzo AR

Family Days
17-19 March 2017

FREE ENTRANCE
ECM credits requested



AIM OF THE CONFERENCE

Mc Cune-Albright Syndrome (MAS, OMIM # 174800) is a rare congenital sporadic disorder with an estimated prevalence ranging from 1 in 1,00,000 to 1 in 100,000. MAS is caused by a post-zygotic somatic activating mutation of the GNAS gene resulting in an increased Gs α protein signaling leading to hyperfunction of glycoprotein hormone receptors, autonomous cell proliferation, and hormonal hypersecretion. The mosaic constitutive activation of this signal transducer is clinically evident with a scattered hyperfunction of endocrine tissues with a wide phenotypic spectrum. MAS classical phenotype, described for the first time in 1937, includes the clinical triad of bone fibrous dysplasia (BFD), café-au-lait skin spots due to skin dysplasia, and peripheral precocious puberty (PPP). However clinical history, basic research and molecular diagnostic studies demonstrate a wide range of severity and prevalence of several clinical manifestations in different ages: hyperthyroidism, hypercortisolism, hyperpituitarism, kidney phosphate wasting, and other rare manifestations can be present. EAMAS and MAS-Bone Fibrous Dysplasia Italian Network, during this meeting, want to analyze quality of life and health needs about transitional care from pediatric to adult age, to strengthen diagnosis and clinical management and to expand clinical and patient international network..

FRIDAY 17th MARCH

ASSOCIATION MEETING

Minerva Hotel Arezzo

VIA Fiorentina, 4 - 52100 AREZZO AR

15:00 Guided Tour Arezzo Historical Center

20:00 Dinner at the Hotel Minerva

21:30 EAMAS Association meeting



SATURDAY 18th MARCH

Fibrous Dysplasia and Mc Cune-Albright Syndrome

Transition to adult age

CENTRO CHIRURGICO TOSCANO

Via dei Lecci, 22 Arezzo

PROGRAM OF THE DAY

FIRST SESSION, chairman R. Lala

9:00 Introduction

V. Dal Pos

Patient's care experiences (testimony) M. Campanini

9.20 Basic research about Fibrous Dysplasia

up-to-date report, application of mice models

M. Riminucci, A. Corsi

9:50 Molecular diagnostic techniques in Fibrous Dysplasia and in McCune-Albright Syndrome

L. de Sanctis

10:20 The concept of transition

R. Lala

10:50 Transitional care: quality of life, health needs and less common manifestations

D. Tessaris

11:10 Coffee-break

11:20 Fertility and sexual function: the woman

P. Matarazzo

11:40 Fertility and sexual function: the man

M. Wasniewska

12:00 Bone health of young adult: clinical researcher experience

A. Boyce

12:30 Bone health of young adult: rheumatologist experience

M. K. Javaid

13:00 – 14:00 Interval

SECOND SESSION, chairman E. Ippolito

14:00 Transitional care from Radiologist experience

C. Defilippi

14:20 Bone health of young adult: orthopedic experiences

E. Ippolito, G. Beltrami

14:50 The emergency surgery

L. Marciandi

15:00 Craniofacial fibrous dysplasia: neurosurgical surgeon point of view

L. Genitori

15:30 Craniofacial fibrous dysplasia: maxillofacial surgeon point of view

G. Spinelli

16:00 Craniofacial fibrous dysplasia: odontostomatologist point of view

P. Defabianis

16:30 The international network: clinicians, researchers and patients - roundtable

S. Bertelloni, V. Dal Pos, L. Ruotolo, G. Weber,
Associations from other EU Countries, all lecturers

17:30 Conclusions and questions from the audience

17:50 ECM questionnaire and credits completion

R. Lala, E. Ippolito

18:10 Completion of work and delivery of forms for ECM credits

ECM Credits requested

SUNDAY 19th MARCH

FAMILY DAY

CENTRO CHIRURGICO TOSCANO

Via dei Lecci, 22 Arezzo

09:00 Proposal for a Cristian Catholic Mass

10:00 Coordination

V. Dal Pos

Introductory contribution

G. Fenocchio

Patient's story telling and dialog with specialists

The participation is open to all specialists

A. Boyce, G. Beltrami, A. Corsi, E. Ippolito, R. Lala,
M. Riminucci, D. Tessaris, ...

Debate and questions from the audience

Suggestions for topics and common issues

12:00 Individual meetings with specialists (*)

Sequence of pre-scheduled meetings

Coordination: A. Dal Ferro, V. Dal Pos, L. Milani

13:00 Lunch

14:00 Individual meetings with specialists (prosecution)

16:00 End of the day and farewell

INFORMATION FOR FAMILIES

HOW TO PARTICIPATE

The intention to participate at the event must be notified as soon as possible to the address listed on the back of this brochure, however within 5th February 2017. Contextually we require, to whom is needing Hotel reservation, an advance payment of € 50,00 by transfer to the bank account n° IT65T010300100000003440054 specifying "VII Eamas Conference". The declaration of intention to attend should include the number of participants, arrival & departure date and time, kids' number, single rooms request and any other special needs regarding hotel accommodation, food intolerances and anything appropriate to be considered.

For the occasion it has been taken an agreement with the hotel Minerva at a cost of € 78,00 double room including breakfast buffet.

HOTEL Minerva, Via Fiorentina 4, 52100 Arezzo AR
www.hotel-minerva.it

(*) INDIVIDUAL MEETINGS WITH THE SPECIALISTS

A special attention must be applied for the organization of the individual meetings with specialists. The request to meet specialists must be sent with the confirmation of participation at the event together with a brief explanation of the topics to be discussed. The families have to prepare, at its own care, the patient's file that should be organized at the best, with the most recent information in evidence, in order to minimize the evaluation time. Thanks for your kind cooperation.