



RIPID

**RARE PULMONARY DISEASES
AND
ORPHAN DRUGS
IN RESPIRATORY MEDICINE**

FIRST "RIPID" INTERNATIONAL CONGRESS

MILAN ITALY FEBRUARY 25-26, 2005

***RARE PULMONARY DISEASES AND ORPHAN DRUGS
IN RESPIRATORY MEDICINE***

MILAN, FEBRUARY 25-26, 2005

ORGANIZED BY

U.O. PNEUMOLOGIA – OSPEDALE SAN GIUSEPPE - MILAN
PROGETTO RIPID

PRESIDENT

S. HARARI

SCIENTIFIC COMMITTEE

C. AGOSTINI (PADUA)
C. ALBERA (TURIN)
M. LUSUARDI (CORREGGIO)
B. MURER (MESTRE)
A. PESCI (PARMA)
V. POLETTI (FORLÌ)
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G.F. RIZZATO (MILAN)
A. ROSSI (PAVIA)
M. SCHIAVINA (BOLOGNA)
C. TINELLI (PAVIA)
M. ZOMPATORI (PARMA)

SCIENTIFIC SECRETARIAT

A. CAMINATI
G. PACIOCCO

ORGANIZING SECRETARIAT

VICTORY PROJECT CONGRESSI
VIA MODENA 3A - 20129 MILAN
PHONE +39.02.89053524 FAX +39.02.201395
INFO@VICTORYPROJECT.IT

LOCATION

MILAN, CONGRESS CENTER PALAZZO DELLE STELLINE



- 8.45 INTRODUCTION AND REGARDS TO THE PARTICIPANTS
- 9.00 LECTURE
CLINICAL AND MOLECULAR INSIGHTS IN LYMPHANGIOLEIOMIOMATOSIS
J. MOSS (BETHESDA, USA)
- 1ST SESSION**
IDIOPATHIC INTERSTITIAL PNEUMONITIS (IIP)
CHAIRMEN: *JF. CORDIER (LYON, FRANCE), S. HARARI (MILAN, ITALY),
B. MURER (MESTRE, ITALY)*
- 9.30 PRIMUM MOVENS: EPITHELIUM, ENDOTHELIUM OR ...WHATEVER?
F. CALABRESE (PADUA, ITALY)
- 9.50 CYTHOKINES, CHEMOKINES AND OTHER BIOMOLECULAR MARKERS IN IIP:
THEIR ROLE IN THE PATHOGENESIS AND TREATMENT
C. AGOSTINI (PADUA, ITALY)
- 10.10 WHICH PROGNOSTIC INDICATOR SHOULD WE USE FOR THE CLINICAL
PRACTICE IN THE INITIAL EVALUATION AND FOLLOW-UP OF IIP: SHOULD
WE STAND ON PFT, HRCT OR ... WHATEVER?
A. CAMINATI (MILAN, ITALY)
- 10.30 DISCUSSION
- 10.50 COFFEE BREAK
- 2ND SESSION**
IDIOPATHIC INTERSTITIAL PNEUMONIA AND DIFFUSE PARENCHYMAL LUNG DISEASES
CHAIRMEN: *R. DU BOIS (LONDON, ENGLAND), V. POLETTI (FORLÌ, ITALY),
C. SALTINI (ROME, ITALY)*
- 11.10 STEROID AND/OR OTHER IMMUNOSUPPRESSIVE THERAPIES IN IIP: HAVE
THEY STILL A ROLE?
L. RICHELDI (MODENA, ITALY)
- 11.30 IDIOPATHIC INTERSTITIAL PNEUMONIA: FROM NEW ETIOPATHOGENETIC
CONCEPTS TO NEW THERAPEUTIC APPROACHES
T.E. KING (SAN FRANCISCO, USA)
- 11.50 AN INTEGRATED CLINICAL APPROACH TO CYSTIC LUNG DISEASES (LAM AND HX)
S. HARARI (MILAN, ITALY)
- 12.10 IS ALVEOLAR PROTEINOSIS AN AUTOIMMUNE DISEASE?
U. COSTABEL (ESSEN, GERMANY)
- 12.30 LUNG TRANSPLANTATION FOR RARE PULMONARY DISEASES
J. EGAN (DUBLIN, IRELAND)
- 12.50 DISCUSSION
- 13.15 LUNCH

**3rd SESSION - EUROPEAN EXPERIENCES ON RARE PULMONARY DISEASES AND ORPHAN DRUGS**

CHAIRMEN: *V. FOGLIANI (MILAZZO, ITALY), G. GIRBINO (CATANIA, ITALY), A.M. MORETTI (BARI, ITALY), G.P. SEMENZATO (PADUA, ITALY)*

- 14.30 ORPHAN DRUGS: WHICH QUALITY?
S. GARATTINI (MILAN, ITALY)
- 14.50 THE GERMOP EXPERIENCE
JF. CORDIER (LYON, FRANCE)
- 15.10 RIPID: THE ITALIAN EXPERIENCE IN RARE LUNG DISEASES
C. TINELLI (PAVIA, ITALY)
- 15.30 SCREENING FOR ALPHA-1 - ANTITRYPSIN DEFICIENCY IN ITALY
M. LUISETTI (PAVIA, ITALY)
- 15.45 CLINICAL TRIALS IN RARE DISEASES
M. CICARDI (MILAN, ITALY)
- 16.00 A PATIENT PERSPECTIVE
TBA
- 16.15 INDUSTRY AND RARE DISEASES
A. SCHWEBIG (PARIS, FRANCE)
- 16.30 ITALY - RARE DISEASES AND ORPHAN DRUGS
D. TARUSCIO (ROME, ITALY)
- 16.45-17.30 ROUND TABLE
DISCUSSANT: *E. DAINA (BERGAMO, ITALY), S. HARARI (MILAN, ITALY), C. SALTINI (ROME, ITALY), G. SIMONNEAU (PARIS, FRANCE), AND ALL THE SPEAKERS AND CHAIRMEN OF THE AFTERNOON*

**4TH SESSION - PULMONARY HYPERTENSION: AN INTERDISCIPLINARY CHALLENGE, AN EXAMPLE FOR OTHER DISEASES**

CHAIRMEN: *P.G. AGOSTONI (MILAN, ITALY), C. ALBERA (TURIN, ITALY), D. VIZZA (ROME, ITALY)*

- 9.00 LECTURE
A LESSON LEARNED BY IDIOPATHIC PULMONARY HYPERTENSION: HOW TO FIGHT A RARE DISEASE
G. SIMONNEAU (PARIS, FRANCE)
- 9.30 IDIOPATHIC PULMONARY HYPERTENSION: WHAT DID WE LEARN FROM GENES
M. HUMBERT (PARIS, FRANCE)
- 9.50 USE OF NON INVASIVE PARAMETERS IN THE CLINICAL PRACTICE FOR PULMONARY ARTERIAL HYPERTENSION EVALUATION
G. PACIOCCO (MILAN, ITALY)
- 10.10 IDIOPATHIC PULMONARY HYPERTENSION: WHICH THERAPY FOR WHICH PATIENT
A. MANES (BOLOGNA, ITALY)
- 10.30 DISCUSSION
- 11.00 COFFEE BREAK

6TH SESSION – LUNG INVOLVEMENT IN SYSTEMIC DISEASES

CHAIRMEN: *J. MOSS (BETHESDA, USA), M. SCHIAVINA (BOLOGNA, ITALY), G. SIMONNEAU (PARIS, FRANCE)*

- 11.30 LUNG INVOLVEMENT IN SYSTEMIC VASCULITIS
A. PESCI (PARMA, ITALY)
- 11.50 LUNG INVOLVEMENT IN CONNECTIVE TISSUE DISEASES
R. DU BOIS (LONDON, ENGLAND)
- 12.10 DISCUSSION
- 12.30 LECTURE
DOES THE NEW ERS/ATS CLASSIFICATION OF CHRONIC INTERSTITIAL PNEUMONIA FIT?
T.E. KING (SAN FRANCISCO, USA)
- 13.00 FINAL COMMENTS



WORKSHOP ITALIANO DEL RIPID

14.30 Lettura
Linfangioleiomiomatosi in Italia
M. Schiavina (Bologna)

Casi clinici con discussione interattiva (I parte)

Moderatori: *F. Bariffi (Napoli), M. Lusuardi (Correggio),
A. Rossi (Pavia)*

Discutono: *C. Albera (Torino), B. Murer (Mestre),
G.F. Rizzato (Milano), M. Zompatori (Parma)*

Caso 1: presentato da *M. Majori (Parma)*

Caso 2: presentato da *A. Sanduzzi (Napoli)*

Caso 3: presentato da *M. Confalonieri (Trieste)*

Casi clinici con discussione interattiva (II parte)

Moderatori: *M. Chilosì (Verona), N. Crimi (Catania),
M. Maffessanti (Trieste)*

Discutono: *G.F. Farinelli (Roma), V. Poletti (Forlì),
G. Salomoni (Milano), G. Vecchi (Milano)*

Caso 4: presentato da *P. Rottoli (Siena)*

Caso 5: presentato da *G. Dalpiaz (Bologna),
A. Cancellieri (Bologna)*

Caso 6: presentato da *L. Longo (Milano), E. Uslenghi (Milano)*

17.00 Lettura
Genetica e Malattie Rare: cosa abbiamo imparato e cosa ci aspettiamo di imparare
M. Luisetti (Pavia)

17.30 Chiusura dei lavori

FACULTY

C. AGOSTINI (PADUA, I)
P.G. AGOSTONI (MILAN, I)
C. ALBERA (TURIN, I)
F. BARIFFI (NAPLES, I)
F. CALABRESE (PADUA, I)
A. CAMINATI (MILAN, I)
A. CANCELLIERI (BOLOGNA, I)
M. CHILOSI (VERONA, I)
M. CICARDI (MILAN, I)
M. CONFALONIERI (TRIESTE, I)
J.F. CORDIER (LYON, F)
U. COSTABEL (ESSEN, D)
N. CRIMI (CATANIA, I)
E. DAINA (BERGAMO, I)
G. DALPIAZ (BOLOGNA, I)
R. DU BOIS (LONDON, UK)
J. EGAN (DUBLIN, IRL)
G.F. FARINELLI (ROME, I)
V. FOGLIANI (MILAZZO, I)
S. GARATTINI (MILAN, I)
G. GIRBINO (CATANIA, I)
S. HARARI (MILAN, I)
M. HUMBERT (PARIS, F)
T.E. KING (SAN FRANCISCO, USA)
L. LONGO (MILAN, I)
M. LUISETTI (PAVIA, I)
M. LUSUARDI (CORREGGIO, I)
M. MAFFESSANTI (TRIESTE, I)
M. MAJORI (PARMA, I)
A. MANES (BOLOGNA, I)
A.M. MORETTI (BARI, I)
J. MOSS (BETHESDA, USA)
B. MURER (MESTRE, I)
G. PACIOCCO (MILAN, I)
A. PESCI (PARMA, I)
V. POLETTI (FORLÌ, I)
L. RICHELDI (MODENA, I)
G.F. RIZZATO (MILAN, I)
A. ROSSI (PAVIA, I)
P. ROTTOLI (SIENA, I)
G. SALOMONI (MILAN, I)
C. SALTINI (ROME, I)
A. SANDUZZI (NAPLES, I)
M. SCHIAVINA (BOLOGNA, I)
A. SCHWEBIG (PARIS, F)
G.P. SEMENZATO (PADUA, I)
G. SIMONNEAU (PARIS, F)
D. TARUSCIO (ROME, I)
C. TINELLI (PAVIA, I)
E. USLENGHI (MILAN, I)
G. VECCHI (MILAN, I)
D. VIZZA (ROME, I)
M. ZOMPATORI (PARMA, I)

GENERAL INFORMATION

Organizing Secretariat

Victory Project Congressi
Via Gustavo Modena, 3a - 20129 Milan - Italy
Phone: +39 02.89.05.35.24 Fax: +39 02.20.13.95
e-mail: info@victoryproject.it

Secretariat on Site

Secretariat and Registration Desk in Congress Venue will be on duty on:

| | | | |
|-----------------------|-------|---|-------|
| Friday, February 25 | 08.00 | - | 18.00 |
| Saturday, February 26 | 08.30 | - | 17.30 |

Technical exhibition

An exhibition of scientific and technical equipments will be organized in the Congress Area. Interested firms are kindly requested to contact the Organizing Secretariat to obtain the exhibition kit with full information.

Certificate of attendance

A certificate of attendance will be given to all registered participants upon presentation of their badge at the Secretariat Desk on Saturday, February 26.

ECM accreditation for Italian participants

The program will be submitted for accreditation for Continuing Medical Education.

Language

Italian and English are the official languages of the Congress.
Simultaneous translation will be available.

Computer Centre

Only PC data projection will be available during the Congress.
Conference room will be provided with a laptop, therefore the use of one's laptop will not be allowed. To allow a smooth running of sessions, Speakers are requested to contact the Computer Centre and hand in their CD at least one hour before the beginning of their session.

CONGRESS VENUE

Congress Venue

Palazzo delle Stelline
Corso Magenta, 61 – 20123 Milan, Italy

Located right in the centre of Milan and at walking distance from the S. Maria delle Grazie Church and the Castello Sforzesco fortress, the Palazzo delle Stelline was a 15th century monastery. The original building has been recently refurbished and restored through the addition of full-view windows installed in the cloister.

In the refectory of the Monastery of Santa Maria delle Grazie, the most famous fresco in the world by Leonardo da Vinci “The Last Supper” (painted between 1495 and 1497), after restoration works, is once again open to the public.

How to reach the Congress Venue

☞ By Plane

From Malpensa Airport: take the train "Malpensa Express" and stop in Cadorna Station.

From Linate Airport: take the bus 73 to San Babila Square and then the Underground Red Line and stop in Cadorna Station.

☞ By Train

From Central Railway Station take the Underground Green Line and stop in Cadorna Station.

☞ By Car

From any highway exit, follow indications “Centro” and then ask for “piazza Cadorna”. In piazza Cadorna you are at 10 minutes walking to the Congress Venue. Parking facilities are available near the Congress Venue

☞ By Local Transportations

- * Underground Line 1, Red – Cadorna Stop
- * Underground Line 2, Green – Cadorna Stop
- * Bus: nr. 54, nr. 70, nr. 94
- * Tram: nr. 19, nr. 27, nr. 29

REGISTRATION

Registration prices are in Euro and include VAT

| | | |
|-----------|--------------------|-------------------|
| | Before November 30 | After November 30 |
| Physician | 350,00 € | 400,00 € |

Registration fee covers:

- Admission to the Scientific Sessions (included the Italian Workshop of Ripid)
- Coffee and lunch buffet
- Congress kit

Registration fee only for Workshop Italiano del RIPID 60,00 €

Only registered participants are allowed to attend the scientific sessions.
After February 10, 2005 only registrations on site at the New Registration Desk in the Congress Venue will be accepted.

Instructions for payment

Payment of registration fee can be effected by:

- International check payable to Victory Project Congressi Srl (please enclose copy)
- Bank Transfer (please enclose copy) to:

Victory Project Congressi Srl
UniCredit Banca - Credito Italiano
Agenzia 24 - Milan, Italy
Account n. 9340484
ABI 02008 - CAB 01624 - CIN L

For this kind of payment, participants are absolutely requested to notify the bank of their complete name and address and the reason for the payment. Bank expenses must be on participant's charge.

Please note that only registrations accompanied by the relevant payment will be processed

Cancellations and refund

In case of cancellation of the registration, you are kindly requested to contact the Organizing Secretariat by January 10, 2005. A 70% of paid fee will be refunded.

Please note that no refund will be made for cancellations notified after this date.

HOTEL RESERVATION

Hotel reservation

All those interested in making hotel reservation are kindly requested to send the enclosed form, by October 30, 2004, to:

Victory Project Congressi
Via Gustavo Modena, 3a - 20129 Milan - Italy
Fax: +39 02.20.13.95
e-mail: info@victoryproject.it

Due to the great demand for hotel rooms, we cannot guarantee any hotel reservation after expiration of the deadline.

| <u>Hotel</u> | <u>Single</u> | <u>Double used single</u> | <u>Double</u> |
|----------------------------|---------------|---------------------------|---------------|
| Palazzo delle Stelline *** | 107,00 € | 127,00 € | 160,00 € |
| Capitol Millennium **** | 180,00 € | 215,00 € | 240,00 € |
| King Hotel *** | - | - | 220,00 € |
| Sant' Ambroeus *** | 117,00 € | 137,00 € | 170,00 € |

The above listed rates are expressed in Euro and are per room per night, including continental breakfast, services and taxes.

All the hotels are located at a walking distance from the Congress Venue.

Instructions for hotel payment

The total prepayment of the requested nights and a booking fee of € 15,00 per room are requested.

Payment of hotel accommodation can be effected by:

- International check payable to Victory Project Congressi Srl (please enclose copy)
- Bank Transfer (please enclose copy) to:

Victory Project Congressi Srl
UniCredit Banca - Credito Italiano
Agenzia 24 - Milan, Italy
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Bank expenses must be on participant's charge.

Please note that only requests accompanied by the relevant payment will be processed

Cancellations and refund

In case of cancellation of the hotel booking you are kindly requested to contact Victory Project Congressi by December 30, 2004. No refund will be made for hotel rates.

*Rare Pulmonary Diseases and Orphan Drugs
in Respiratory Medicine
Milan, February 25-26, 2005*

To be sent to (preferably within November 30, 2004):

VICTORY PROJECT CONGRESSI
Via Gustavo Modena 3a – 20129 Milan - Italy
Fax + 39 02 20 13 95
e-mail info@victoryproject.it

PLEASE FILL IN THIS FORM USING A TYPEWRITER OR BLOCK LETTERS

Last Name
First Name
Address for invoice
.....
Zip Code City
Country
Phone Fax
E-mail
Institute
Department
C.F. / P.Iva (for Italian residents only)

Registration fees (prices are in Euro and include VAT):

| | Before November 30 | After November 30 |
|--|--------------------|-------------------|
| <input type="checkbox"/> Physician | 350,00 € | 400,00 € |
| <input type="checkbox"/> Workshop Italiano del RIPID (only Saturday Feb 26 afternoon) | 60,00 € | |

REGISTRATION FORM b

Payments methods

- International check payable to Victory Project Congressi Srl (please enclose copy)
- Bank Transfer (please enclose copy) to:

Victory Project Congressi Srl
UniCredit Banca - Credito Italiano
Agenzia 24 - Milan, Italy
Account n. 9340484
ABI 02008 - CAB 01624 - CIN L

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Bank expenses must be on participant's charge.

Please note that only registrations accompanied by the relevant payment will be processed

I enclose the following amount

Registration fee(s): €

€

Total €

Date Signature

*Rare Pulmonary Diseases and Orphan Drugs
in Respiratory Medicine
Milan, February 25-26, 2005*

To be sent to (preferably within October 30, 2004):

VICTORY PROJECT CONGRESSI
Via Gustavo Modena 3a – 20129 Milan - Italy
Fax + 39 02 20 13 95
e-mail info@victoryproject.it

PLEASE FILL IN THIS FORM USING A TYPEWRITER OR BLOCK LETTERS

Last Name

First Name

Address for invoice

.....

Zip Code City

Country

Phone Fax

E-mail

Institute

Department

C.F. / P.Iva (for Italian residents only)

| <u>Hotel</u> | <u>Single</u> | <u>Double used single</u> | <u>Double</u> |
|----------------------------|---------------|---------------------------|---------------|
| Palazzo delle Stelline *** | 107,00 € | 127,00 € | 160,00 € |
| Capitol Millennium **** | 180,00 € | 215,00 € | 240,00 € |
| King Hotel *** | - | - | 220,00 € |
| Sant' Ambroeus *** | 117,00 € | 137,00 € | 170,00 € |

Hotel prices are in Euro and are per room per night, including continental breakfast, services and taxes.

HOTEL ACCOMMODATION FORM b

Please reserve for me:

Nr. room/s Single Double used single Double

Preferably at Hotel

Arrival date Departure date

Payments methods:

International check payable to Victory Project Congressi Srl
(please enclose copy)

Bank Transfer (please enclose copy) to:

Victory Project Congressi Srl
UniCredit Banca - Credito Italiano
Agenzia 24 - Milan, Italy
Account n. 9340484
ABI 02008 - CAB 01624 - CIN L

For this kind of payment, participants are absolutely requested to notify the bank of their complete name and address and the reason for the payment.

Bank expenses must be on participant's charge.

Please note that only hotel requests accompanied by the relevant payment will be processed

I enclose the following amount:

Hotel payment: €

Booking fee of € 15,00 : €

Total €

Date Signature

*Privacy-Italian Law n. 675/96 – We warrant complete privacy on personal data.
They will be used only for communications concerning the meeting organization.*