



Ospedale Niguarda

Sistema Socio Sanitario



Regione
Lombardia

ALBINIT 



OSPEDALE SAN RAFFAELE

APRIL, 7th AND 8th, 2016

III EDA 3rd European Day of Albinism

Medical Section
Association Section
Psyco pedagogical Section

LOMBARDY REGION BUILDING
Piazza Città di Lombardia, Milan, Italy



ALBINIT with Niguarda Hospital organize, at the Lombardy Region Building in Milan, the Third European Days of Albinism (IILEDADA).

Meeting point for researchers focused on albinism, international associations of patients and their families to discuss both scientific and social aspects of this rare pathology, exchanging ideas, projects and initiatives.

A satellite meeting concerning the psycho-pedagogic aspects of this disease will be held simultaneously.

The meeting is divided into three sections:

- Room 5
Medical Section:
Physicians, Biologists and Researchers (only for operators in the albinism sector) - **p.1**
ECM credits: 8.40
- Room 4
Associations Section:
only for representatives of Associations - **p.6**
- Room Biagi
Psycho pedagogical Section:
Orthoptists, Speech therapists, Laboratory technicians, social and health educators - **p.8**
ECM credits: 4.90

The Opening Ceremony and the Plenary final session are in the Room Biagi.

MEDICAL SECTION

7/4/2016

- 8.00 - 8.30** Registration
- 8.30-9.00** Opening ceremony
Representative of the Region, G.P.Gesu, A.Marocchi, R.Masto, L.Paschetta, E.Tronconi
- 9.00-10.00** **SCIENTIFIC SESSION I:
CLINICAL DEFINITION OF ALBINISM**
- Chair: I.Gottlob, E.Piozzi
- 9.00-9.20** Expanding the phenotype of albinism?
B.Käsmann-Kellner
- 9.20-9.40** Phenotypic spectrum in FHONDA and albinism
M.Van Genderen
- 9.40-10.00** *Discussion*
- 10.00-11.30** **SCIENTIFIC SESSION II:
CLINICAL AND MOLECULAR DIAGNOSIS OF ALBINISM**
- Chair: K.Grønskov, S. Scalinci
- 10.00-10.20** Postnatal retinal development in albinism as compared to healthy controls
I.Gottlob

- 10.20-10.40** Visual cortex in albinism - anatomy and function
M.Hoffmann
- 10.40-10.55** *Contribution of electrofunctional examinations in albinism diagnosis*
A.P.Tormene
- 10.55-11.15** Molecular diagnostic approaches: Targeted sequencing, exome, array-CGH?
B.Arveiler
- 11.15-11.30** *Discussion*
- 11.30-12.00** *Coffee break*
- 12.00-13.30** **SCIENTIFIC SESSION III:
EUROPEAN DIAGNOSTIC EXPERIENCES**
- Chair: A.Del Longo, A.Taïeb, P.Primignani
- 12.00-12.20** Clinical and molecular experience in Denmark
K.Grønskov
- 12.20-12.35** Clinical and molecular experience in Italy
L.Mauri , R.Terrana
- 12.35-12.50** Albino Day in Madrid
M.Cortón
- 12.50-13.05** Albino Day in Bordeaux
F.Maurice-Picard
- 13.05-13.30** *Discussion*
- 13.30-14.40** *Lunch break*

14.40-16.00 **SCIENTIFIC SESSION IV:
PATHOGENESIS OF ALBINISM**

Chair: L.Montoliu, M.V.Schiaffino

14.40-15.00 Understanding visual defects in albinism using mouse and cellular models
A.Rebsam

15.00-15.20 Syndromic albinism disorders affecting membrane trafficking during melanosome formation
M.Marks

15.20-15.40 Evidence for melanosomal channels and transporters critical for pigmentation
E.Oancea

15.40-16.00 *Discussion*

16.00-16.30 *Coffee/Tea break*

16.30-18.10 **SCIENTIFIC SESSION V:
BEYOND EYES**

Chair: B. Arveiler, S.Penco

16.30-16.50 Oculocutaneous albinism in East and Southern Africa
P.Lund

16.50-17.10 Skin photoprotection issues in albinism
A.Taïeb

17.10-17.30 Dermatological characterization in Italian albinos
D. Calò

17.30-17.50 Audiological deficits in albinos: correlation with genetic/clinical phenotype
G.Mingoia

17.50-18.10 *Discussion*

8/4/2016

8.30-10.00 **SCIENTIFIC SESSION VI
TECHNICAL SUPPORT AND THERAPEUTIC FRONTIERS**

Chair: B.Käsmann-Kellner, A.Del Longo

8.30-8.45 Visual management training in low vision patients
F.Fabiani

8.45-9.05 Pharmacological therapy
B.Brooks

9.05-9.20 Defining safety and efficacy end-points for OCA1 gene
therapy-based clinical studies
E.Surace

9.20-9.40 New animal models of albinism generated with CRISPR tools
L.Montoliu

9.40-10.00 Discussion

10.00-10.30 **FINAL SCIENTIFIC DISCUSSION**

Chair: I. Gottlob, A.Marocchi, L.Montoliu, M.V.Schiaffino

10.30-13.30 **PLENARY FINAL SESSION**

10.30-11.00 Summary of scientific presentations
B.Käsmann-Kellner , M.C.Patrosso

11.00-11.20 Summary of psycho pedagogical presentations
M. Nalli

- 11.20-11.50** Summary of association's presentations
A. Glikshon
- 11.50-12.00** "Kindness for Kid"
- 12.00-12.10** Dermatological prevention
F. Brunetta
- 12.10-12.20** Photografic project "Every color of the White" presentation
- 12.20-13.30** Global discussion - Suggestions about guide lines on Albinism-
Proposal for the next meeting

ASSOCIATIONS SECTION

7/4/2016

8.00 - 8.30 Registration

8.30-9.00 Opening ceremony
Representative of the Region, G.P.Gesu, A.Marocchi, R.Masto, L.Paschetta, E.Tronconi

9.00-18.30 **MORNING SESSION**

9.00-10.00 Presentations of new online Associations

10.00-13.30 **Report Section on activities in different countries**
Defense of the Albino rights

11.45-12.10 Coffee break

Alliances with Public Administrations

Initiatives of social and scientific disclosure on this rare genetic condition

Albinism and technologies

13.30-14.40 Lunch break

14.40-18.15 **EVENING SESSION**

“Wina” Project Presentation: mobility and new frontiers

16.00-16.30 Coffee/Tea break

Albinism and European federation: state of art and new steps

Europe and Africa: alliances and projects

8/4/2016

10.30-13.30 **PLENARY FINAL SESSION**

10.30-11.00 Summary of scientific presentations
B.Käsmann-Kellner , M.C.Patrosso

11.00-11.20 Summary of psycho pedagogical presentations
M. Nalli

11.20-11.50 Summary of association's presentations
A. Glikshon

11.50-12.00 "Kindness for Kid"

12.00-12.10 Dermatological Prevention

12.10-13.30 Global discussion-Presentation of leaflet/book on albinism for
the general public-Proposal for the next meeting

PSYCO PEDAGOGICAL SECTION

7/4/2016

- 8.00 - 8.30** Registration
- 8.30-9.00** Opening ceremony
Representative of the Region, G.P.Gesu, A.Marocchi, R.Masto, L.Paschetta, E.Tronconi
- 9.00-10.00** **I SESSION**
- Chair: E. Tronconi
- 9.00-9.20** The special needs in the education of albino children
L.D'Alonzo
- 9.20-9.40** Verona response to the needs of young families: "Associative support desk for visually impaired children for family awareness and for the rehabilitation planning, after first diagnosis"
M.Nalli
- 9.40-10.00** Who benefited from the project Hypovision: Help Space. Detailed quantitative and qualitative considerations
G.Zampieri
- 10.00-11.00** **II SESSION**
- Chair: L. D'Alonzo
- 10.00-10.20** The experience at the Center for Pediatric Ophthalmology of Verona: the interaction between clinicians, families and educator of Help Space!
E.Gussone, I.Tomaello
- 10.20-10.40** Where the resistance to resilience are higher: support residential projects
E.Vlacos

10.40-11.00 From the analysis of the request to the understanding of child with visual impairment in the consultation stage at the Fondazione Robert Hollman
E. Mercuriali

11.00-11.50 **III SESSION**

Chair: M. Nalli

11.00-11.15 The multisensoriality as resource and educational strategy
M. Boneschi

11.15-11.35 A rehabilitative approach for integrating visually impaired child: the experience of the children low vision center IRCCS.E. Medea
G. Giammari, D. Valli

11.35-11.50 The experience of the Blind Institute of Milan: the educational activities for pupils with albinism in the context of services for visually impaired
F. Lisi

11.50-12.10 Coffee break

12.10-13.30 **III SESSION**

Chair: E. Piozzi

12.10-12.30 Dyslexia, pathophysiology and rehabilitation
S. Scalinci

12.30-12.50 The taking into care of the visually impaired child rehabilitation for different age groups: the intervention model of Chiossonne Institute
E. Cocchi

- 12.50-13.10** The achievement of the autonomy in the visual impaired person: can be done?
S.Presti
- 13.10-13.30** The visually impaired student: strategies for school inclusion
S.Benedan
- 13.30-14.30** Lunch break
- 14.30-18.30** **ROUND TABLE**
STATE OF THE ART OF THE LAWS IN MATTERS OF INCLUSION
- Chair: F.Castronovo, R.Di Lorenzo, R.Garlaschelli, G.Merlo, S. Nocera, S.Parolini, L.Paschetta, L.Pellegrini Marchesini
- Map of the educational services for children with sensory disabilities offered by the region
- The usefulness of educational support Help Desk
- The services offered by CTS-NTD: the case of Como
- The alternation between school and work, an important tool for the life project of people with albinism
- The role and responsibilities of the supporting teacher
- An associative experience of welcome and service in Sicily
- School and social inclusion
- Discussion and Conclusion
- 16.45-17.15** Coffee/Tea break

MEDICAL SECTION SPEAKERS

ARVEILER BENOÎT

Geneticist
Medical Genetic
University of Bordeaux, F

MARTA CORTÒN

Biomedical Research
Genetics and Genomics Department
Institute-Jimenez Diaz Foundation University Hospital, E

ALESSANDRA DEL LONGO

Ophthalmologist
Paediatric Ophthalmology
Niguarda Hospital, Milan, IT

FLAVIA FABIANI

Ophthalmologist
Hypovision Center
Ospedali Riuniti di Bergamo, IT

IRENE GOTTLOB

Ophthalmology
Ophthalmology Group
University of Leicester, UK

KAREN GRØNSKOV

Ophthalmogenetic Researcher
Cellular and Molecular Medicine
Kennedy Medical Genetics, DK

MICHAEL HOFFMANN

Ophthalmologist
Ophthalmology Department
University of Magdeburg, D

PATRICIA LUND

Geneticist
School of Life Science
Faculty of Health and Life Sciences, UK

BARBARA KÄSMANN-KELLNER

Ophthalmologist
Department of Ophthalmology
University of Saarland, D

MICHAEL S MARKS

Pathologist
Department of Pathology and Laboratory Medicine
Children's Hospital of Philadelphia Research Institute, USA

ALESSANDRO MAROCCHI

Pathologist
"Emeritus Department Head"
Niguarda Hospital, Milan, IT

RODOLFO MASTO

Special Commissioner
Istituto dei Ciechi di Milano, IT

LUCIA MAURI

Geneticist
Medical Genetics
Niguarda Hospital, Milan, IT

GIUSEPPE MINGOIA

Otolaryngologist
ORL Clinic
Università di Milano Bicocca, IT

LLUIS MONTOLIU

Research Scientist
Department of Molecular and Cellular Biology
Centro Nacional de Biotecnología, E

DONATA CALO'

Dermatologist
Medicine Department
Niguarda Hospital, Milan, IT

ELENA OANCEA

Researcher
Department of Molecular Pharmacology, Physiology and Biotechnology
Brown University, USA

LUCIANO PASCHETTA

Director
Istituto per la Ricerca la Formazione e la Riabilitazione, IT

MARIA CRISTINA PATROSSO

Geneticist
Ethics Committee
Niguarda Hospital, Milan, IT

SILVANA PENCO

Geneticist
Medical Genetic
Niguarda Hospital, Milan, IT

FANNY MAURICE PICARD

Paediatric Dermatologist
Department of Paediatric Dermatology
Bordeaux University Hospital, F

ELENA PIOZZI

Ophthalmologist
Paediatric Ophthalmology
Niguarda Hospital, Milan, IT

PAOLA PRIMIGNANI

Geneticist
Medical Genetic
Niguarda Hospital, Milan, IT

ALEXANDRA REBSAM

Researcher
Institut du Fer à Moulin
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SERGIO SCALINCI

Ophthalmologist
Low Vision Academy
Università degli Studi of Bologna, IT

MARIA VITTORIA SCHIAFFINO

Researcher
Group Leader, Dibit
San Raffaele Hospital, Milano, IT

ENRICO MARIA SURACE

Researcher
TIGEM
Telethon Institute of Genetics and Medicine

ALAIN TAÏEB

Dermatologist
Department of Dermatology
University of Bordeaux, F

ROBERTA TERRANA

Ophthalmologist
Paediatric Ophthalmology
Niguarda Hospital, Milan, IT

ALMA PATRIZIA TORMENE

President International Society for Clinical Electrophysiology of Vision, IT

ELISA TRONCONI

President ALBINIT, IT

MARIA VAN GENDERN

Ophthalmologist
Department of Visual Diagnostics
Bartiméus Institute for the Visually impaired, NL

PSYCO PEDAGOGICAL SECTION SPEAKERS

SONIA BENEDAN

Tiflogloga
Servizio socio-educativo
Centro Non Vedenti -Brescia

MARCO BONESCHI

Psicologo
Associazione Nazionale Subvedenti

FRANCO CASTRONOVO

Docente di Tecnologia
Area Sostegno alla Persona (DA, DSA, BES) - Como

ELENA COCCHI

Psicologa
Istituto David Chiossone per i Cechi e gli Ipovedenti
Centro di Riabilitazione delle Disabilit  Visive

LUIGI D'ALONZO

Pedagogista
Centro studi e ricerche sul disagio e le povert  educative universitarie
Universit  Cattolica di Milano

ROCCO DI LORENZO

Presidente
Associazione Retinopatici ed Ipovedenti Siciliani - ARIS

RITA GARLASCHELLI

Insegnante
Ufficio scolastico per la Lombardia

GIUSEPPINA GIAMMARI

Neuropsichiatra Infantile
Centro Ipovisione dell'Et  Evolutiva
IRCCS "E. MEDEA" - La Nostra Famiglia, (Lecco)

ELENA GUSSON

Oftalmologo
Istituto di Clinica Oculistica
Università di Verona

FRANCO LISI

Direttore Scientifico
Dirigenza Istituto dei Ciechi - Milano

GIOVANNI MERLO

Direttore
Lega per i Diritti delle Persone con Disabilità
Federazione Regionale Lombarda - FISH

MARCELLA NALLI

Pedagogista
Progetto vederesentire
SocioCulturale Cooperativa Sociale Onlus - Mestre , Venezia

SALVATORE NOCERA

Avvocato
Federazione Italiana per il Superamento dell'Handicap - Roma

STEFANO PAROLINI

Rappresentante
Settore Socio Educativo e Socio Assistenziale
SocioCulturale Cooperativa Sociale onlus - Mestre, Venezia

LUCIANO PASCHETTA

Psicologo
Federazione Associazioni Nazionali Disabili

LUCIA PELLEGRINI MARCHESINI

Rappresentante ALBINIT

ELENA PIOZZI

Oftalmologa
Oculistica Pediatrica
Ospedale Niguarda, Milano

SEBASTIANO PRESTI

Vice Presidente

Associazione Nazionale Istruttori Orientamento Mobilità Autonomia Personale
Brescia

SERGIO SCALINCI

Oftalmologo

Low Vision Academy

Università degli Studi of Bologna

ELENA MERCURIALI

Psicologa

Fondazione R. Hollman - Padova

ILARIA TOMAELLO

Ortottista

Oculistica

A.O. Universitaria Integrata di Verona

ELISA TRONCONI

Presidente ALBINIT

DANIELA VALLI

Pedagogista

Associazione La Nostra Famiglia

IRCCS "E.Medea", (Lecco)

ELENA VLACOS

Psicoterapeuta

Servizio di Neuropsichiatria Infantile

Fondazione Istituto Neurologico Nazionale "C. Mondino", (Pavia)

GIOVANNI ZAMPIERI

Pedagogista

Ce.Di.Sma

Università Cattolica di Milano

REGISTRATION

Medical section

Physicians, Biologists and Researchers (only for operators in the albinism sector)

ECM credits: 8.40

Online Registration: albinit.org/progetti/IIIEDA

Maximum number of participants: **80**

Registration cost:

- 250,00 € for Physician, Biologist or Researcher (information regarding included services on (<http://albinit.org/progetti/IIIEDA/>))
- 80,00 € for Student – Fellow - Laboratory technicians
- free registration for internal employees

The meeting will be held in English

Psyco pedagogical section

Orthoptists, Speech therapists, Laboratory technicians, social and health educators

ECM credits: 4.90 (credits will be awarded to teachers and University students)

Online Registration: albinit.org/progetti/IIIEDA

Maximum number of participants: **200**

Registration cost:

- 80,00€
- free registration for internal employees

L'incontro si terrà in italiano.

SCIENTIFIC ADVISOR

ELENA PIOZZI

Paediatric Ophthalmology Director
Niguarda Hospital, Milan, IT

SECRETARIAT

Maria Cristina Patrosso
crisrina.patrosso@gmail.com

HOW TO REACH THE MEETING

Lombardy Region Building can be reached with MM2 (Gioia stop)

Patronages



Milano

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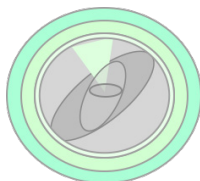
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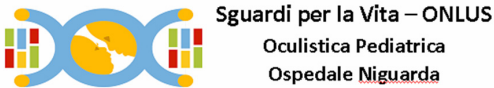


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