



# It's worth it!

#coma #after\_coma #acquired\_brain\_injuries

#EUComaAwakeningsDay

#

EUROPEAN  
DAY OF  
AWAKENINGS  
OCTOBER 7<sup>TH</sup> 2020

COMA  
AND ITS  
OUTCOMES



www.studifiro.it

After the isolation that we all had to face because of the pandemic, the “National Day of awakenings on coma research – It’s worth it”, has a greater meaning this year. It is promoted by “Gli amici di Luca” organizzazione di volontariato (Friends of Luca voluntary organization), that comes to the goal of its 22<sup>th</sup> edition and it celebrates the 6<sup>th</sup> “European Day of Awakenings”.

This particularly difficult moment that had repercussions even in the tertiary sector has obliged our association to make deep evaluations without suspending the relationships with our patients with outcomes from brain injuries who returned home on the territory and their relatives, trying to make feel our affinity and support from remote.

Now that we are gradually coming back to a new normality, by shared registers with institutions to preserve the health of all the citizens, we are about to celebrate the next DAY OF AWAKENINGS with an improved energy and equal dedication. The pathologies we are taking care of cannot be left behind, not even just because they are indirectly struck by the pandemic that has diverted attentions and resources from them. Patients with outcomes from coma and severe acquired brain injuries do urgently now require greater attention in order to make their rights and problems be visible and their needs to be constantly and consciously identified by institutions in charge.

On October 7<sup>th</sup> the next “Day of awakenings” will deal with the above-mentioned issues and it will analyse social and clinical themes about research. It will be done through the social campaign of our testimonial Alessandro Bergonzoni and two webinar conferences on “BIOETHICS AND THE FIVE SENSES” and the perspectives of the second “NATIONAL CONFERENCE ON CONSENSUS OF THE ASSOCIATIONS” that represent the relatives taking care of patient in coma, vegetative state or ABI. Furthermore, the theatre company Gli amici di Luca composed by patients who came out from coma will bring their own experience in a new performance called “Absences: diversimili in progress”, (Different-similar in progress) set up on the occasion at the Teatro Dehon in Bologna.

The event of information on coma, the vegetative state and severe acquired brain injuries once again creates networks with different Italian cities and other European countries, to make public opinion aware, give voice to patients with outcomes from coma and their families, shed light on criticalities of the care and analyse new frontiers of research.

Since 1999 this initiative has reinforced in time and it has took on a European dimension thanks to the projects carried out by the association through the synergy with the institutions, partner countries and the patronage of the European parliament that has joined the historical High Patronage of the President of the Republic.

The “Day of Awakenings” is born from the project of the “Casa dei Risvegli Luca De Nigris” (Luca De Nigris House of Awakenings) that is shared with the Municipality of Bologna. This public centre of the Local Health Authority is specialised in innovative rehabilitation and research and it is unique in Europe; it is part of the area of the hospital “Bellaria” and it strengthens a new philosophy of the cure and enhances the central role of the family.

The Association Gli amici di Luca is present in the “Osservatorio Nazionale sulla Condizione delle Persone con Disabilità” (National Observatory on the conditions of persons with disability) and it is involved in the application of the action plan that endorses the United Nations Convention on the rights of patients with disabilities and the commitment on equal opportunities of disadvantaged patients.

[www.amicidiluca.it](http://www.amicidiluca.it)



With the patronage



ALMA MATER STUDIORUM UNIVERSITÀ DI BOLOGNA



Cambia il movimento

With the patronage and the contributions of



ASSOCIAZIONE VOLONTARI ITALIANI SANGUE ODV

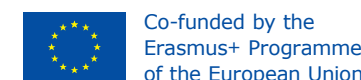
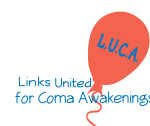
in cooperation with



Associazioni Riunite per il Trauma Cranico e le Gravi Cerebrolesioni Acquisite



European projects and partners



Salvare vite e dare un futuro alle persone

## GENERAL PROGRAM



**San Pellegrino Terme | Saturday, September 26<sup>th</sup>, 2020 - h. 9.00 a.m / 1.30 p.m.**  
*Hotel Bigio - Centro Congressi - Via Giacomo Matteotti, 2 - San Pellegrino Terme - Bergamo*

### 32° GENESIS MEETING

CONVENTION

## INNOVATIVE ASPECTS ON THERAPY, CARE AND REHABILITATION IN NEUROLOGICAL DISEASES

WITH THE PATRONAGE OF

**Fondazione Bergamasca**

**Dipartimento Riabilitativo di Bergamo (Rehabilitation Department, Bergamo)**  
**La Rete (Ass. Naz. per il Trauma Cranico) (National Association for Head Injury)**

**AIMS OF THE CONVENTION:** to face in an updated, simple but exhaustive way the current problems about clinical diagnosis, the care and rehabilitation treatment of neurological diseases. To focus on the disease with a multidisciplinary approach: clinical, physiopathological, therapeutic and rehabilitative; to consider the therapy of disorders in neurological diseases, to offer an update of the reasonable use of the different available therapies; to manage the nursing of the patient with neurological disorders in hospitals and in the area, to analyse rehabilitative techniques suitable for patients with neurological diseases.



Secretarial services – Scientific secretary Dr. **Giovanni Pietro Salvi**  
 Istituto Clinico Quarenghi - San Pellegrino Terme - Tel. +39 0345 25145 - segreteria@clinicquarenghi.it

**Bologna | Sunday, October 4<sup>th</sup> - from 10.00 a.m**

*Piazza Maggiore - Bologna*

**AS PART OF THE CELEBRATIONS FOR SAN PETRONIO**



CHIESA DI BOLOGNA

## THE FRIENDS OF LUCA AND THE CITY: HOW TO OUTCOME COMA AND COME BACK TO LIFE

Presentation of the project:

LA BOTTEGA DELLE MANI E DELLA MENTE (The hand and mind workshop)

The recovery of social life after the experience of the House of Awakenings Luca De Nigris sometimes notices very severe obstacles inside the family unit who hosts the patient with severe residual disabilities. Patients have to face the new kind of life and to create different balances after the traumatic event. Among these difficulties, there is the problem of how to spend spare time.


This project, supported by the Curia of Bologna, organizes and carries out rehabilitative laboratories and group resocialisation projects both for the patient with disabilities and the caregiver.

During the morning, awareness and recreational, motoric activities in cooperation with



Comitato Provinciale di Bologna



 Bologna | Wednesday, October 7<sup>th</sup> - h. 10-12.30 a.m / 2.30-4.30 p.m.  
Giardino Casa dei Risvegli Luca De Nigris (The House of Awakenings Luca De Nigris Garden)  
Via Giulio Gaist, 6 - Bologna

## THE DAY OF AWAKENINGS - OPEN DAY

In cooperation with



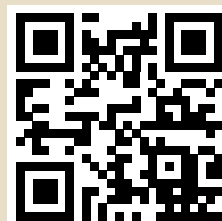
PROGRAM

- Recreational and motoric activities for youngsters and citizenry
- Readings and testimonies of patients who came out of coma and their relatives
- Meetings with institutional representatives with the participation of **Alessandro Bergonzoni**, testimonial of the House of Awakenings Luca De Nigris

At 12.00 a.m. the “**Messaggi per un Risveglio**” (*Messages for an Awakening*) attached to ecological balloons will fly from the House of Awakenings and at the same time from different Italian and European squares involved in the event.

From 2.30 p.m. **Trail-O** (*Trail Orienteering; precision orienteering*) in cooperation with Polisportiva Masi in Casalecchio di Reno, CIP Comitato Italiano Paralimpico (Italian Paralympic Committee) - Emilia Romagna. It is a discipline of orienteering that does not consider to reach physically the points of control positioned on the competition grounds, but to identify them, always using maps and compass, looking at them from observation points duly signalled along the paths that are easily accessible and walkable.


For information - Tel 051 6494570 - [www.amicidiluca.it](http://www.amicidiluca.it)

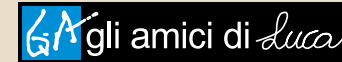


QR code for registration  
Or type: [bit.ly/amicidiluca](http://bit.ly/amicidiluca)

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 Bologna | Wednesday, October 7<sup>th</sup> - h. 9.00 p.m.  
Teatro Dehon - Via Libia, 59 - Bologna



present

## ABSENCES: DIVERSIMILI IN PROGRESS

(DIFFERENT-SIMILAR IN PROGRESS)

Performance realised by patients who came out from coma and attended the theatre labs of the House of Awakenings Luca De Nigris

With the group “**Dopo...di Nuovo, Gli amici di Luca**” in presence and on video  
Conducted and directed by **Alessandra Cortesi**  
Pedagogical coordination **Antonella Vigilante**

With the “**Compagnia Gli amici di Luca**” in presence and on video  
Directed by **Deborah Fortini**  
Pedagogical coordination **Martina Pittureri**  
Theatre coordination **Nicola Bonazzi**

partners:

**DEHON**.teatroaperto  
TEATRO STABILE DELL'EMILIA-ROMAGNA



Since 2003 the Association is active in the field of cultural activities (theatre, music, cinema, editing and publication of books) finalized to the reacquisition of competences and abilities of fragile patients (mainly with outcomes from coma). In 2004 the “Space of the Arts” was created at the House of Awakenings Luca De Nigris: a place where it is possible to express and experiment, that from its “protected” and “involved” dimensions it intends to open mainly to the outside, towards those who are “not involved”.

The performance “**Assenze: diversimili in progress**” (*Absences: different-similar in progress*) is born within the scope of the project “**Diversimili: coma to community**” (*Different-similar project: coma to community*) co-funded by the European Union, European Social Fund, Operational Program Metropolitan Cities 2014-2020. From January 2020 to October 2021 a



Photos Gabriele Ffiole

planning ability that considers to realise workshops of theatre, music, audiovisual and awareness action will take place through programmed events between the House of Awakenings Luca De Nigris, the spaces in the Neighborhood, the High Schools, the University and the City Theatres. The intention is to intercept a welcoming and involving community and to integrate it with the “marginality” through activities directed to patients with disorders and outcomes from coma. The performance enhances the criticalities experienced during the lockdown that have forced us to revise our interventions without losing the relationships, the contacts and the expressive potentialities of the participants.



Co-funded by the European Union | European Social Fund | Operational Program Metropolitan Cities 2014-2020

 Bologna | From Wednesday, October 7<sup>th</sup> to Tuesday 20<sup>th</sup>  
Teatro Dehon - Via Libia, 59 - Bologna

**PHOTOGRAPHIC EXHIBITION**

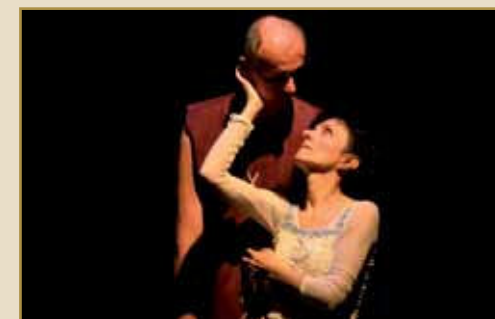
## **I AM AMLE TO BUT I HAVE THAT WITHIN WHICH PASSES SHOW THESE BUT THE TRAPPINGS AND THE SUITS OF WOE**

*Realised by the Associazione Fotografica Tempo e Diaframma curated by Gabriele Fiolo*

The long experience with Hamlet has produced a photographic exhibition that tells the creative and descriptive path realised through the theatre lab, an instrument used to go along with fragile patients on their way to recover, to tighten and reinforce relations that bring them out of social isolation.

I AM AMLETO is the moment in which every participant has confronted themselves with their competences and relational abilities drawing gratification. It is also a support for those memories that are easily lost if they are not supported. This exhibition is realised by the photographers Gabriele Fiolo and Cristina Ferri, for the association Tempo e Diaframma.

*Realised with the contribution of*



Photos Gabriele Fiolo

Malta | From Thursday, October 1<sup>th</sup> to Sunday 4<sup>th</sup>

WEBINAR PROGRAM ON ZOOM PLATFORM

CONFERENCE

# INTERNATIONAL BIOETHICS CONFERENCE

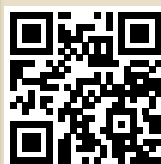
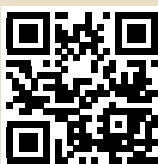
## Bioethics and the Five Senses: Between Clinical Practice and Metaphors



*ECM credits for all health professions have been requested  
and granted by the Provider ECM PG20120131897*

An interesting conference promoted by the **University of Malta** and addressed to all the health professional involved in health care or health management, as well as those who are interested in Bioethics in general.

It is organised by the Professional Ethics Platform inside the Department of Moral Theology under the supervision of rev. doct. **Ray Zammit**, with the expert cooperation of prof. **Pietro Grassi** as scientific consultant.



For information on the program and registration  
<https://bioethics5senses.net>

To apply for ECM credits  
(for Italian citizens)  
[www.amicidiluca.it](http://www.amicidiluca.it)



Federazione Nazionale  
Associazioni Trauma Cranico

With the patronage of

*Ministero della Salute*

**TOWARDS THE SECOND**

# “NATIONAL CONFERENCE ON CONSENSUS OF THE ASSOCIATIONS”

representing the families  
taking care of a patient in coma,  
vegetative state, minimally conscious state,  
and severe acquired brain injury




With the patronage of



FNOMCeO



Istituto delle Scienze Neurologiche  
Istituto di Ricovero e Cura a Carattere Scientifico

 Bologna | Saturday, October 10<sup>th</sup> - h. 8.45 a.m / 1.30 p.m

WEBINAR PROGRAM ZOOM PLATFORM

CONVENTION

## TOWARDS THE SECOND NATIONAL CONFERENCE ON CONSENSUS

*Of the associations that represent the relatives of patients in vegetative state,  
minimally conscious state and ABI*

### THE STATE OF THE ARTS

The convention is a further step to get close to the “Second National Convention on Consensus” promoted by the associations that represent the relatives taking care of a patient in coma, vegetative state, minimally conscious state and severe acquired brain injury.

It all started on February 9<sup>th</sup>, 2019 in Rome in the Auditorium of the Ministry of Health on the occasion of the “National Day of Vegetative States” and through different steps, despite the lockdown. The path has now been resumed on this webinar realised for the Day of Awakenings. The coordination of work groups formed by representatives of the associations and specialists will explain the state of the arts of work; they will confront with the scientific and technical committee trying to answer to relatives’ needs, the questions arising from their role, for quality indicators shared between the health world and that of the associations. A convention on unsatisfied needs and on expected, but still suspended results should end on October 7<sup>th</sup>, 2021 with a document validated by the jury and shared with the institutions.

**8.45 a.m.** Beginning of the conference

**9.00 a.m.** Greetings from the authorities

**Ore 9.15** “The Second Conference on Consensus: future perspectives”

**Gian Pietro Salvi** President of La Rete delle associazioni, President of Genesis

**Maria Vaccari** President of Gli amici di Luca

**Paolo Fogar** President of FNATC (Federazione Nazionale Associazioni Trauma Cranico - *National Federation of the associations for brain injury*)

**9.30 a.m.** “The conference on consensus: the state of the arts”

**Francesco Nonino** and **Luca Vignatelli** (IRCCS Istituto delle Scienze Neurologiche - *Institute of Neurological Science*, Bologna)

**9.45 a.m.**

Interventions of workgroup coordinators

**Ezio Torrella** (Torrella & Conforti - Avvocati law firm, Bologna)

The rights of patients with disabilities - legal protection and regulations

**Ivana Cannoni** (ATRACTO Association, Montevarchi)

The role of the associations representing families and the role of the caregivers

**Maria Teresa Angelillo** (Uniti per i risvegli Association, Bari),

Quality standards in healthcare facilities: in the post-acute rehabilitative phase and in the chronic phase

**10.00 a.m.** Break

**10.45 a.m.**

**Elena Di Girolamo** (Rinascita e Vita association, Genova)

Possible quality standards in the return home and programs for an independent life:

**Lucia Lucca** (S. Anna Institute, Crotone)

The networks and the coma to community model

**Fabio La Porta** (Casa dei Risvegli Luca De Nigris, Bologna)

The Right to research and the development of research

**Maria Grazia Inzaghi** (Quarenghi Clinical Institute, San Pellegrino Terme, Bergamo)

Formation, communication and narration paths for family support

**Anna Di Santantonio** (Gli amici di Luca Association, Bologna)

The return to work after ABI: definition of a model of holistic and multidisciplinary vocational rehabilitation.

**12.00 p.m.** Break

**12.30 p.m.** discussion with the representatives of the Technical and Scientific Committee and the Associations

**Roberto Piperno** (IRCCS Istituto delle Scienze Neurologiche, Bologna);

**Rita Formisano** (Santa Lucia IRCCS Foundation, Roma);

**Matilde Leonardi** (IRCCS Istituto Besta Foundation, Milano);

**Anna Mazzucchi** (IRCCS Don Gnocchi Foundation, Parma);

**Antonio De Tanti** (Centro Cardinal Ferrari, Fontanellato - Parma);

**Anna Estraneo** (IRCCS Don Gnocchi Foundation, Florence);

**Francesco Napolitano** (“Risveglio” Association, Roma);

**Elena Villa** (Arco92 Association, Roma);

**Giancarlo Pivetta** (Gli amici di Ale Association, Pordenone);

**Gianluigi Poggi** (Insieme per Cristina Association, Bologna).

**13.30 p.m.** Conclusion of the work

Moderator **Fulvio De Nigris** (Promoting committee and director of the Centro Studi per la Ricerca sul Coma, Gli amici di Luca, Bologna)

Secretariat Gli amici di Luca

Patrizia Boccuti - Info and registrations:

Tel. 051 6494570 - patriziab@amicidiluca.it

Many thanks for the cooperation



 Lithuania | Thursday, October 8<sup>th</sup>

1<sup>st</sup> Part - Siauliai University - University library - Vytauto str., 84 - Lithuania

2<sup>nd</sup> Part - Kurtuvėnai Regional Park - Parko g. 2 - Kurtuvėnai - Siauliai reg. - Lithuania

## CREATING WELLBEING TOGETHER

Participants of the event: People awakening after coma and their family members, specialists working with persons awakening after coma – rehabilitation, education, social workers; representatives of Siauliai Municipality, representatives from Public Health Office, representatives of Siauliai University, representatives of Kurtuvėnai Regional Park, NGO's working with persons awakening after coma.

### *Program of the event*

#### *1<sup>st</sup> Part*

##### *Event at Siauliai University*

10.00 a.m. Welcoming speeches by Rector of Siauliai University prof. dr. **D. Šiaučiūnas**, representative Siauliai Public health Department PhD.

**Saulius Vaivada**, Vice – Mayor of Siauliai City **Egidijus Eljosiū**.

10.30 a.m. Social Inclusion of Awakenings through Spots Activities:  
Sharing of good experience. (lect. **L. Miliuniene**).

10.50 a.m. Sport and neurological rehabilitation after coma (neurologist **A. Kazlauskas**).

11.15 a.m. Education and occupation problems of persons awakening after coma.  
Case study. (lect. prof. **L. Radzeviene**).

#### *2<sup>nd</sup> Part*

##### *Event at Kurtuvėnai Regional Park*

12.30 a.m. Hypotherapy sessions: reflections of people awakening after coma and their family members and practical activities (participants, specialists working with this target group in NVO's, team of Siauliai University).

1.30 p.m. Nutrition and sport activity of awakenings' after coma.  
Practical session (lect. **I. Dobrovolskytė**).

2.30 p.m. Excursion - exploration „History and famous places of Kurtuvėnai“  
(guided by representative of Kurtuvėnai Regional Park) with the barbeque party

5.30 p.m. End of the event.

 Cyprus | Wednesday, October 7<sup>th</sup>

Piazza Centrale di Lemesos - Lemesos

## ESFC European Social Forum Cyprus

Awareness raising activities through social media (Facebook page “LUCAS Project”) and newspapers; various testimonies and interviews (that of a member of the European Parliament is foreseen).

 Denmark | From Thursday, November 5<sup>th</sup> to Friday 6<sup>th</sup>

Università di Aalborg - Fredrik Bajers Vej 5 - Aalborg - Danimarca

## International conferences ArtsIT and DLI 2020

EAI ArtsIT 2020 (9<sup>th</sup> EAI International Conference: ArtsIT, Interactivity & Game Creation) and EAI DLI 2020 (5<sup>th</sup> EAI International Conference on Design, Learning & Innovation)

 Spain | Friday, October 16<sup>th</sup> - h. 9.45 a.m / 11.30 a.m

Nueva Opción - Calle Greses 21 - València

Association of Acquired Brain Injury of the Valencia Province  
[comunicacion@nuevaopcion.es](mailto:comunicacion@nuevaopcion.es)

CONVENTION IN VIDEO CONFERENCE

## ALTERED STATES OF CONSCIOUSNESS: THE GOOD PRACTICES OF HUMANISATION

Commemorative GIF for the “European Day of Awakenings” on social media

 Portugal | Tuesday, October 6<sup>th</sup> - h. 6.00 p.m.

Cascais, Porto e Braga

MEETING ONLINE ON THE ZOOM PLATFORM

Presentation and debate of the theme

## BURNOUT AND CARETAKERS

Promoted by Novamente

Association of support to patients with cephalic traumas and their families

We are considering inviting the following panel speakers:

- **Silvia Artilheiro Alves** president of the Portuguese association of caretakers.
- One of our caretakers for a personal history.
- **Vera Bonvalot** novamente executive director .
- And a clinical Psychologist.

the National Day of Awakenings is supported by



Thanks to Claudia Romagnoli for the English version