



Under the High Patronage of the President of the Republic



It's worth it!



EUROPEAN DAY OF AWAKENINGS

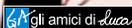
OCTOBER 7TH 2019



With the support of the Lifelong Learning and the Erasmus+ Programme of the European Union



Co-funded by the Erasmus+ Programme of the European Union



With the patronage



SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA
Azienda Unità Sanitaria Locale di Bologna

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



With the patronage and the contributions of



in cooperation with



European projects



The “National Day of Awakenings for coma research - It’s worth it” promoted by “Gli amici di Luca voluntary organization” has come to the goal of its twenty - first edition and it celebrates the fifth “European Day of Awakenings”.

The event of information about coma, the vegetative state and serious acquired brain injuries comes once again to make a network with several Italian town as well as other European countries, to raise awareness in the public opinion, give voice to patients with coma outcomes and their families, in order to show criticalities in home care and to examine in depth the new frontier of research. Since 1999 this initiative has got stronger in time and it has acquired a European Dimension due to the projects realized by the association Gli Amici di Luca through its synergy with the institutions, partner countries and the patronage of the European Parliament who joined the historic High Patronage of the President of the Republic. The “Day of Awakenings” arises from the project of the “House of Awakenings Luca De Nigris” shared with the Municipality of Bologna, a unique public centre for rehabilitation and research of the local health authority in Bologna. This centre has been created in Bologna in the area of the “Bellaria” hospital; it strengthen a new philosophy of the cure and it enhances the central role of the family, wishing the expansion of similar structures in a network of services suitable for patients with coma results and vegetative state.

The National Day of Awakenings has acquired a European dimension thanks to the already settled European project LUCA (Links United for Coma Awakenings) and LUCAS (Links United for Coma Awakenings through Sport), whose leader is the training organization Futura, in cooperation with CSI Centro Sportivo Italiano (Italian Sports Centre) and the Association Gli amici di Luca, the latter has been selected as “success story” by a group of experts of the General Directorate of Education, Youth, Sport and Culture of the European Commission.

These projects have come to start a debate on the theme of coma that has risen great interest at European level thus allowing the theatre activities expressed by the workshops with patients who outcome from coma in the House of Awakenings Luca De Nigris to be extend abroad as well, thanks to the support of the Regione Emilia Romagna Cultura d’Europa and the Municipality of Bologna. This year as well the event will be carried out through a rich program of initiatives and joined actions among the participating countries dealing with social themes, together with clinical ones such as the research and the therapeutic alliance among health professionals, not healthcare operators, family members and volunteers. In particular, in Italy, in Bologna the conference “Towards the second NATIONAL CONFERENCE ON THE CONSENSUS OF THE ASSOCIATIONS” (representing family members who take care of a dear one in a coma, vegetative state or with severe acquired brain injury) with the patronage of the Ministry of Health, Fiaso, Fnomceo, Rete Italiana Città Sane and many precious subscriptions, with the participation of specialists, experts and representatives of the associations from all over Italy. The association “Gli amici di Luca” is present in the “National Observatory on condition of Patients with Disabilities” and it is active in the application of the action plan endorsing the United Nation Convention on the rights of Patients with Disabilities and the commitment on equal opportunities of patients with disabilities.



PROGRAM OF THE EVENT



San Pellegrino Terme | Saturday 21 September 2019 - 9.00 a.m./1.30 p.m.

Hotel Bigio - Centro Congressi - Via Giacomo Matteotti, 2 - San Pellegrino Terme - Bergamo

31° MEETING GENESIS

CONFERENCE

Innovative aspects of therapy, care and rehabilitation in neurologic diseases

WITH THE PATRONAGE OF

Fondazione Bergamasca

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



Secretariat - Scientific Secretariat Dr. **Giovanni Pietro Salvi**

Istituto Clinico Quarenghi - San Pellegrino Terme - Tel. 0345 25145 - segreteria@clinicaquarenghi.it

Bologna | Friday 4 October 6.00 p.m.

Spazio Mediateca - Via Caselle, 22 - San Lazzaro di Savena - (Bo)

INAUGURATION OF THE PHOTOGRAPHY EXHIBITION I AM HAMLET

Realized by the Associazione Fotografica Tempo e Diaframma by Gabriele Fiolo

(opened until 12 October)

Gabriele Fiolo art director of the Photography Association *Tempo e Diaframma*, has been cooperating with Gli amici di Luca for many years realizing many photos during the past performances and taking part with the association to two past editions of “M’illumino di meno” (Lighting up less) promoted by Caterpillar Rai2.

Introduced by a short performance of the group “Dopo...di nuovo, Gli amici di Luca”, the exhibition supports the new project realized by the association Gli amici di Luca and the cooperative TeatroAperto Teatro Dehon following the project “Amleto Experience” through expressive laboratories where the integration of the photographic set becomes the support of a fragile memory, thus allowing to catch experiences that could get lost. The photographic documentation gives back to the protagonists a new, stronger and more efficient image of itself. Among its goals the expressive path has that of supplying opportunities to patients who lived the experience of coma, in order to outcome social isolation.

With the contribution of



FONDAZIONE DEL MONTE
DI BOLOGNA E RAVENNA
1471



Bologna | Sunday 6 October 10.00 a.m./3.00 p.m.

Via Rizzoli - Bologna

WALKING TOGETHER: Gli amici di Luca and the city

in cooperation with *Trekking Italia Emilia Romagna*

Urban trekking from the headquarters of the association Gli amici di Luca Voluntary Organization (via Saffi 8) to via Rizzoli

LUCA'S COMMUNITY: motor and sport paths and experiences of well being



LUCA'S COMMUNITY is the awakening, the return to life in a path of reappropriation of one's existence and re-socialization, the acquisition of new abilities, against limitations. The project intends to create an active community and to promote through motor and sport activities correct lifestyles and experiences dedicated to patients who come out of coma, motor and cognitive disabilities and their families in order to improve both health and well being.

Initiatives to raise awareness on sports complying with exhibitions.



Energy Sports centre



Bologna | Monday 7 October 9.00 a.m. - 12.30 a.m.

Garden of the Casa dei Risvegli Luca De Nigris - Via Giulio Gaist, 6 - Bologna

DAY OF AWAKENINGS - OPEN DAY

in cooperation with the *CSI Centro Sportivo Italiano Comitato di Bologna*
(Italian Sports centre Bologna committee)

For many years the “National Day of Awakenings” is traditionally an opportunity to meet citizens to state the need of looking at differences, expressing solidarity, rejoicing and celebrating together in a care location linked to the city in order to reiterate its normality with patients, families, operators and volunteers.

PROGRAM

LUCA'S COMMUNITY: motor and sport paths and experiences of well being

- Recreational and motor activities for youngsters of the elementary school realized by the operators CSI Centro Sportivo Italiano *Italian Sports Centre*
- Readings of *Legg'io* in the setting of the pact for reading of Bologna 11.30 a.m. Greetings from authorities, with the participation of **Alessandro Bergonzoni**, testimonial of the Casa dei Risvegli Luca De Nigris.

Some Italian towns will take part to the Day of Awakenings for Coma Research with different initiatives: **Gioia del Colle (BA), Pescara, Salerno, Caltagirone (CT), San Paolo Solbitro (AT), Agnone (IS), Cremona.**



Energy Sports centre



With the patronage of
 Ministero della Salute
 (Ministry of Health)

SECOND

“NATIONAL CONFERENCE ON CONSENSUS OF THE ASSOCIATIONS”

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

 gli amici di Luca



 Bologna | Monday 7 and Tuesday 8 October - 9.00 p.m.

ITC Lab - Via Rimembranze, 26 - San Lazzaro di Savena - (Bo)

*Gli amici di Luca and Teatro dell'Argine
 perform*

OVVERO IO

Directed by Deborah Fortini

*From the theatre lab for patients with outcomes from coma in the
 “Casa dei Risvegli Luca De Nigris”*

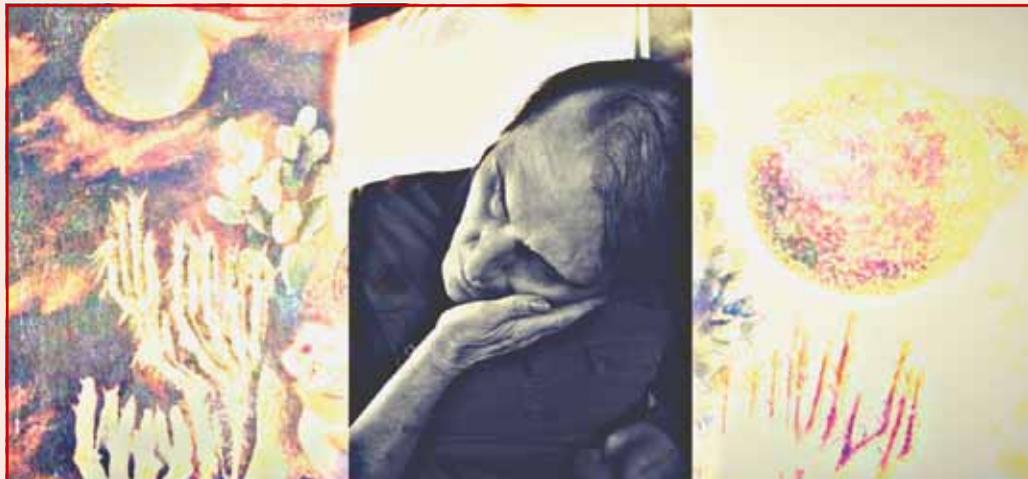
To spread through the theatre a culture of responsible legality and citizenship for an alliance between institutions and civil society to oppose social inequality: this is the path started by Gli amici di Luca on the twenty-first “National Day of Awakenings”.

This initiative involves patients with coma outcomes, families and actors in theatrical labs inside the House of Awakenings Luca De Nigris, a public structure of the local health authority in Bologna in agreement with the association Gli amici di Luca Voluntary Organization; with the goal of the formation and the education of the citizens: those who are “Not involved”, those the spokesperson of the association, Alessandro Bergonzoni, deals with.

The final result of the theatrical path lead by Nicola Bonazzi and Deborah Fortini of the Teatro dell'Argine is the performance “Ovvero io”, dealing with the docking to a stage that is different from the usual ones: la racetrack of a circus, where the protagonists will meet their own self, overcoming the tear inflicted to life in a path from: “What we were” to “what we aren't anymore”. The stories of “our actors” intertwine with those of other protagonists who have won their personal fight with the failures of life: like the poet Pierluigi Cappello or the paintress Frida Khalo.

From the notes of direction by Deborah Fortini: “What we were and what we are. What we are similar to. Stories overlap. Characters overlap. In other words them. In other words me”.

Free offer entrance



Bologna | Saturday 12 October - 10.00 a.m./6.00 p.m.

Auditorium Enzo Biagi - Biblioteca Sala Borsa - Piazza del Nettuno, 3 - Bologna

TOWARDS THE SECOND NATIONAL CONFERENCE ON CONSENSUS

Of the associations representing the families of patients in vegetative state, minimally conscious state and TBI

CONVENTION

6 ECM credits have been awarded for all the healthcare professions
And granted by the Provider ECM PG20120131897

Until 2012 in Italy in relation to Severe Brain Injury the conferences of consensus were promoted by scientific societies even if they were shared among associations. In 2012 the first “National Conference on Consensus promoted by the associations” moved the point of view that is proposed in this new second conference. The consensus searched as an answer to the needs of families and to the questions originating from their role, putting into the centre the indicators of quality shared between the healthcare world and the associations. A conference on unsatisfied needs and on the expected and still suspended results. An open initiative to organizations and healthcare and social professionals and to the volunteer world.

PROGRAM

10.00 a.m. Greetings from the authorities
“Why a second Conference on Consensus”

Gian Pietro Salvi *president of La Rete (reunited associations for brain injury and TBI)*

Paolo Fogar *presidente FNATC (Federation of National Associations for Brain Injury)*

Maria Vaccari *president Gli amici di Luca Voluntary Organization*

10.30 a.m. Opening session

Chiara Gibertoni *general director of the Azienda Usl di Bologna, Local Health authority, Bologna*

10.50 a.m. The conference on Consensus: methodological aspects

Luca Vignatelli *Azienda Usl Bologna Local health authority, Bologna*

IRCCS Istituto delle Scienze Neurologiche di Bologna (Institute of Neurological Sciences, Bologna)

Relations of the coordinators of the working groups

11.30 a.m. THE RIGHTS OF THE PATIENTS WITH DISABILITIES – LEGAL AND REGULATORY PROTECTION.

Ezio Torrella *Studio Legale Migliori-Torrella law office*

12.00 a.m. THE ROLE OF THE ASSOCIATION WHO REPRESENT THE FAMILIES, AND THE ROLE OF THE CAREGIVERS

Ivana Cannoni *president of the association A.TRA.C.TO. Onlus, Montevarchi*

12.30 a.m. QUALITY STANDARDS IN CARE FACILITIES:

IN THE POST ACUTE REHABILITATION PHASE AND IN THE CHRONIC PHASE

Maria Teresa Angelillo *vice president of the association Uniti per i Risvegli Onlus, Bari*

United for the Awakenings – Organization with automatic non-profit status

1.00 p.m. light lunch

2.30 p.m. Afternoon session

Reports of the coordinators of the groups of work
POSSIBLE QUALITY STANDARDS IN THE RETURN HOME
AND PROGRAMS FOR AN INDEPENDENT LIFE:

Elena Di Girolamo *president of the association Rinascita e Vita Onlus, Genova*

3.00 p.m. THE NETWORKS AND THE MODEL TO COMMUNITY

Lucia Lucca *physiatrist, responsible for the Unity of Awakening of the Institute Sant’Anna, Crotona*

3.30 p.m. RIGHT TO RESEARCH AND DEVELOPMENT OF THE RESEARCH

Fabio La Porta *medical supervisor, Complex Operative Unit, Rehabilitation Medicine
Department of Emergency - Local Health Authority, Bologna*

4.00 p.m. FORMATION, COMMUNICATION, NARRATION FOR A SUPPORT
PLACEMENT TO THE FAMILY

Maria Grazia Inzaghi *neuropsychologist, Clinical Institute Quarenghi San Pellegrino Terme*

4.30 p.m. THE RETURN TO WORK AFTER BRAIN INJURY: DEFINITION OF A MODEL
OF VOCATIONAL REHABILITATION, HOLISTIC AND E MULTISCIPLINARY

Anna Di Santantonio *psychologist, association Gli amici di Luca Voluntary Organization, Bologna*

5.00 p.m. Discussion

Roberto Piperno *neurologist physiatrist director of the House of Awakenings Luca De Nigris,
Local Health Authority, Bologna*

Anna Mazzucchi *neurologist consultant Fondazione Don Gnocchi*

Antonio De Tanti *Clinical director Centro Cardinal Ferrari, Gruppo Santo Stefano*

Donatella Bonaiuti *physiatrist, council of presidency SIMFER Società Italiana Medicina
Fisica e Riabilitativa / Italian Society of Physical and Rehabilitation Medicine*

Anna Estraneo *Operative unity of neurology, Ospedale Santa Maria della Pietà Nola (NA) and
member of the directive Sirn*

Mauro Zampolini *neurologist physiatrist Ospedale di Foligno*

6.00 p.m. Conclusion of the work

moderator

Fulvio De Nigris *President of the jury and Director of the Study Centre for Coma Research,
Gli amici di Luca Voluntary Organization*

Many thanks for the cooperation



EXPOSANITA'

MED • CARE • INNOVATION

22^a mostra internazionale al servizio della sanità e dell'assistenza

15 | 16 | 17 aprile 2020

BolognaFiere

Secretariat Gli amici di Luca

Patrizia Boccuti - Info and registrations:

Tel. 051 6494570 - patriziab@amicidiluca.it

Bologna | From 15 to 17 October - 9.00 p.m.

Teatro Dehon - Via Libia, 59 - Bologna

DEHON.teatroaperto
TEATRO STABILE DELL'EMILIA-ROMAGNA

Dopo di Nuovo
D&N Gli amici di Luca

Presents:

AMLETO: THE SLINGS AND ARROWS OF OUTRAGEOUS FORTUNE

Directed by Alessandra Cortesi, pedagogical coordination by Antonella Vigilante

Performance in season ticket for prose

info: 051 342934

In October the performance will be on tour to Valencia inside the twinning between the Municipality of Bologna and the Municipality of Valencia and the association Gli amici di Luca Voluntary Organization and the Spanish association Nueva Opción being part of the Spanish association in charge of brain injury.



Photos Gabriele Fiolo

Hamlet, a text that grabs everything; among its words there are love, tragedy, fight, death and not death. The human being is sounded out in every aspect of its own. That is why it is necessary to make choices to reduce and to move it close to a group that is accustomed to express by playing, in performative situations that are not so verbal and very free. Our path is born from the natural challenge given by Shakespeare's words and by a construction that is more rigid and binding than ever. We have accepted the challenge. What of this work has resounded in the group? A father apparently dead yet unrecognisable who can still talk to his son about the betrayal he endured.

If the betrayal was the offence of the disease, that even keeping the shape of the known man, changed its substance? That death – not death that is often imagined for patients during coma and that it seems to be a bit attached to the awakening, too. What else echoes? The difficulty and the charge of the parents and friends who endure the same offence and who wait, fight, believe in what was, and still is, even in a different way, their dear one. Then there is the monologue of monologues, that awesome photograph of the instant of the crisis...To be ready is everything!

In a scene where the written word is fragmented, a myriad of Hamlets, Ophelias, guardian angels, Gertrudes and a Madness that is declined in different shades, are made available for the development of the plot, allowing themselves just the authentic words of the bard. Due to the peculiarities of the group, I chose to strengthen the signs, to repeat them, to multiply, to convey them through different sensorial channels. I do not know, we do not know at first glance neither which proposal could be fixed in a unstable memory, nor which passage of the text could comfort a lonely heart. We use the plurality of signs, voices, bodies; we are strong because we are an odd community and we want to integrate. For these reasons, the theatrical language that better reflects us is the togetherness, as an answer to the individuality that make us more fragile and more different than what we really are.

(from the notes on direction by Alessandra Cortesi)

With the contribution of



The group
"Dopo...di Nuovo, Gli amici di Luca"
In the new production realized with
the Compagnia Teatroaperto/Teatro Dehon



Belgio | Tuesday 24 September*Eventlocatie Den Berg - Bergkapelstraat 98 - 1840 Londerzeel**Thomas More University - Mobilab Expertise Centrum**VOKA Congress Health Community**“The brave and dreamers of today – The creative of the futur”***Post-rehabilitation: challenges, future, programs, conquests, research...***Speeches by**Marc Herremans and Lieven De Maesschalck***Lituania | Tuesday 8 October***1st Part - Siauliai University - Univrsity library - Vytauto str., 84 - Lithuania**2nd Part - Kurtuvenai Regional Park - Parko g. 2 - Kurtuvenai - Siauliai reg. - Lithuania***To create well being together**

Speeches by patients who have awoken from coma and members of their families, specialists of rehabilitation, education, social workers, representatives of the municipality and of Siauliai University, of the Public Health office, of the Kurtuvenai Regional Park, NGO who take care of patients with coma outcomes.

*Program of the event**1st Part**Event at Siauliai University**10.00 a.m. Welcome speeches:*

D. Šiaučiūnas Dean of Siauliai University,
Saulius Vaivada representative of the Public Health Office,
Egidijus Elijosius vice- mayor of Siauliai,
R. Pranskaitis R. Pranskaitis Reverend of the parish of Kairiai Parish.

10.30 a.m. Social inclusion through sports activities of patients who awoke from coma (report by L. Miliuniene).

10.50 a.m. Modern approach to brain functioning (A. Kazlauskas, neurologist).

11.15 a.m. Education and work problems of patients with coma outcomes (report by L. Radzeviciene).

*2nd Part**Event at Kurtuvenai Regional Park*

12.30 a.m. Hippotherapy session. Open air sport activities (participants: patients with coma outcomes and their families, specialists working with this target at NGO; with the group of the project at the Siauliai University).

2.30 p.m. Excursion – exploration “Diversity of Landscape” (lead by the representative of the Kurtuvenai Regional Park).

5.30 p.m. Conclusion of the event.

Cipro | Monday 7 October*Main square in Lemesos - Lemesos***ESFC European Social forum Cyprus**

Intensive plan of action for initiatives of awareness of the European Day of Awakenings: spread of newsletters with bilingual text (in English and Greek), activities of updating of data of NGO in Cyprus and in EU, actions on social networks.

Danimarca | From Wednesday 6 to Friday 8 November*Aalborg University- Fredrik Bajers Vej 5 - Aalborg - Denmark***International conferences ArtsIT and DL I 2019**

Anthony Brooks and Eva Irene Brooks will take part as speakers and they will present the European Day of Awakenings inside the International Conferences ArtsIT (8th International Conference EAI on Arts, Interactivity & Toy Creation) and DLI 2019 (4th International Conference EAI on Design, Education and Innovation) organised by the European Alliance for Innovation (EAI).

Spagna | From Tuesday 1 to Friday 11 October*Nueva Opción - Calle Greses 21 - València**Association of Acquired Brain Injury of the Valencia Province***Coma inside the hospital**

Videoforum with the show of the documentary “COMA” (HBO). Speeches by: clinicians and operators of the association Nueva Opción, testimonies of patients with coma outcomes and their families.

The European Day of Awakenings will be spread also through social networks.

Spagna | Tuesady 24 October - 5.30 p.m.*Teatro Russafa - Carrierr De Denia 55 - València**Gli amici di Luca and TeatroAperto Teatro Dehon in cooperation with Nueva Opción**PRESENT***Amleto Experience**

directed by Alessandra Cortesi, pedagogical coordination by Antonella Vigilante

Portogallo | Monday 7 October*Cascais, Porto and Braga***Open day***Promoted by Novamente**Association of support to patients with cephalic traumas and their families*

A group of patients with TBI outcomes will show their coma experience and the phases of their rehabilitation and social integration.

Coordinator of the event Maria Conceicao Vieira

With the contribution of

