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ed brain\_injuries #**EU**ComaAwakenings**Day** # ewoz#

## ROPEAN VAKENINGS OCTOBER 7<sup>TH</sup> 2018

COMA **OUTCOMES** 

































The "National Day of Awakenings on Coma Researches - It's worth it" has reached this year its twentieth edition and it is now the forth "European Day of Awakenings".

This event comes from the project between the Municipality of Bologna and the "Casa dei Risvegli Luca De Nigris" (Luca de Nigris House of Awakenings) of the Health Authority in Bologna, an innovative and unique public centre in Europe on rehabilitation and research. This centre has been created in the area of Ospedale Bellaria that reinforces a new philosophy of the cure thus enhancing the central role of the family, wishing for the expansion of similar structures in a network of services suitable for patients who woke up from coma and in vegetative state.

Twenty editions are an important goal that rewards the planning ability of a local sensitivity being able to unify the needs of a voluntary association and of the active institution in a common project of social and health innovation. From 1999 to nowadays the event wants to give voice to the patients who woke up from coma and to their families, to highlight the helpful criticalities and to enhance the new frontiers of research.

The National Day of Awakenings has assumed a European dimension thanks to the European projects (already ended) LUCA (Links United for Coma Awakenings) e LUCAS (Links United for Coma Awakenings through Sport) headed by Centro di Formazione Futura (Futura Educational Centre), in cooperation with CSI Centro Sportivo Italiano (Italian Sport Centre) and the Association Gli Amici di Luca, the latter selected as "success story" by a group of experts of the Directorate General of Education, Youth, Sport and Culture of the European Commission.

These projects have led to start a debate on the subject of coma that has raised great interest at European level, allowing the theatre activities of the workshop with patients who woke up from coma of the Luca De Nigris House of Awakenings to be extended even abroad, thanks to the support of the Emilia Romagna region and AMI (Fondazione Alta Mane Italia- Alta Mane Italia Foundation) supporting the Association Gli amici di Luca for many years. Even this year the event will take place through united action among the coun-

tries involved through social themes, together with those clinical on the research and the therapeutic alliance among health professional, non- health operators, members of the families and volunteers. In particular in Italy the themes that will be enhanced deal with the coexistence with the disease, the management of the patients, the support to the families with regards to the "Possibilities and limits of the return to driving after acquired brain damage" through a convention realized with the patronage of the Ministry of Health. The association Gli amici di Luca is also present in the National Observatory of the Condition of People with Disabilities and it is involved in the application of the action plan to approve the United Nation convention on the rights of people with disability and the commitment on equal opportunities of deprived people.

www.amicidiluca.it

### **PROGRAM OF THE EVENT**















#### **Bologna** | until 7<sup>th</sup> October

Manica Lunga di Palazzo d'Accursio - Piazza Maggiore 6 - Bologna

# National Day of Awakenings Alessandro Bergonzoni Twenty years of social advertisement

collection-exhibition































#### San Pellegrino Terme | Saturday 29th September 2018 - h. 9.00/13.30

Hotel Bigio - Centro Congressi - Via Giacomo Matteotti, 2 - San Pellegrino Terme - Bergamo 30° GENESIS MEETING

**CONVENTION** 

## Innovative aspects of therapy, assistance and rehabilitation in severe acquired brain damages

With the patronage of Fondazione Bergamasca 4,9 credits assigned

San Pellegrino Terme | Saturday 20th October 2018 - h. 10.00/18.00

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

## The cranial traumatised, the neurological patient, the family and the health professionals

"The cranial traumatised, the neurological patient, the family and the health professionals" h. 10.00 round table with Italian and French health professionals, social supervisors of the territory, administrators and presidents of the associations

Moderators Fulvio De Nigris and Roberto Piperno

The representatives of **EBIS** (European Brain Injury Society)

And of the UNAFTC (French associations for brain injury) will be present Lunch break

- h. 14.30 Intervention of the relatives to evaluate the needs
- h. 15.00 The history of the Italian associations (Anna Mazzucchi Parma)
- h. 15.30 The mediation in health problems (Jean Luc Truelle Paris)
- h. 16.00 The Italian project on the needs of families (Matilde Leonardi Milan)
- h. 16.30 Neurosystemics
- h. 17.00 The family in the rehab project (**Rita Formisano** Rome)
- h. 17.30 The communication with the families (Maria Grazia Inzaghi Como)
- h. 18.00 The caregiver on the territory (Lucia Lucca Crotone) Conclusions (Antonio De Tanti - Parma)

Sunday morning

Editing of the document on discussed themes, to present to the institutional headquarters Sunday afternoon

Genesis party and meeting with patients and their families

Organizational secretary - Scientific secretary Dr. Giovanni Pietro Salvi Istituto Clinico Quarenghi - San Pellegrino Terme - Tel. 0345 25145 - segreteriasan@clinicaquarenghi.it

#### Bologna | Tuesday 2<sup>nd</sup> October 2018 - h. 18.00

Teatro Arena di FICO - Via Paolo Canali 8 - Bologna

*In cooperation with* 















**SEMINAR** 



## LIFESTYLES:

## BETWEEN RECOVERY AND HEALTH AFTER A BRAIN DAMAGE

discussion led by Fulvio De Nigris

Director of the Study Centre on Coma Research, Gli amici di Luca

participants:

Roberto Piperno

Director of the Luca De Nigris House of Awakenings

Giorgio Cantelli Forti

president ANA

Paolo Pandolfi

Director of the Department of prevention of the Health Authority AUSL of Bologna

Melissa Milani

President of the Emilia-Romagna

Paralympic committe

Silvana Hrelia

Department of Science for the quality of life University of Bologna UNIBO

At 8.30 p.m.

#### **CHARITY DINNER**



€ 35,00 per person In favour of the House of Awakenings CAAB Luca De Nigris

Special thanks to

Info and reservations: Gli amici di Luca Tel. 051 6494570 - info@amicidiluca.it

#### Bologna | Friday 5th October - h. 18.00

Libreria Coop Zanichelli - Piazza Galvani 1H - Bologna

librerie.coop



Presentation of the book

## **Un teatro necessario (A necessary theatre)**

Social study on the impact of theatre in after coma situations

With the author Luca Zappi interventions:

#### Fulvio De Nigris

Director of the Study Centre on Coma Research, Gli amici di Luca

#### Pina Lalli

Department of Social and Political Science Alma Mater Università di Bologna

Theatre operators and people who woke up from coma taking part in the workshops of Casa dei Risvegli Luca De Nigris (Luca De Nigris House of Awakenings)

Moderator:

Massimo Marino

theatre critic and essayist



With the patronage

With the support



This book presents a sociological research on the impact of theatre workshops realized in the house of awakenings Luca De Nigris and aimed at patients who woke up from coma.

It is also the account of a scientific challenge studying less explored fields; it has developed in front of unexpected questions and hidden connections.

Therefore, the question at the basis of this research that the association Gli amici di Luca was interested in verifying - if there was a connection between the establishment of a network of relationships in the theatre workshops and the quality of life - got intertwined with other questions thus highlighting a multicolored and complex sociological "context", made up of instincts, different languages, social networks and much more.

In practice, what do people do when they find themselves in a situation of unusual

relationship, made difficult by the different sensorial equipment at their disposal?

How it is possible to build-apply-invent suitable rules of interaction and of performance able to allow and exchange, even inside a scene where subjects show a different perceptive and locutionary capacity and an uneasy mobility?











ENTRANCE ON DONATION

With contribution



Info: Gli amici di Luca - Tel. 051 6494570 - info@amicidiluca.it

Hamlet, a text that embraces the whole, among its words it is possible to find love, tragedy, comedy, fight, death and non death. The human being sounded out in any aspect. That is why it is necessary to carry out choices to reduce it and to approach to a group that is accustomed to express themselves by playing, in performative situations that are less verbal and mainly free. Our path started from a natural challenge given by the words of Shakespeare and by a more rigid and binding construction than usual; as usual we accepted the challenge. Of this work, what resound in the group?

The focus of the performance is an apparently dead father, who, even if at a distance, can still talk to his son who is orphan because of a betrayal. And if the betrayal was the offence of the disease that, even preserving the form of the known man, changes his substance? That death-not-death that is often imagined for the people during coma that seems to remain a bit attached at the awakening as well. What else? The difficulty and the burden of parents and mates that suffer the same offence and who wait, fight and believe in who the person was and still is a dear one, even if in a different way. And then there is the monologue of monologues, that photograph of the instant of crisis...

To be ready is everything...

In a scene where the written word is fragmented, seven Hamlets, seven Ophelias, seven guardian angels, five Gertrudes and a Madness declined in different shades, are at the disposal of the development of the plot, granting only the authentic words of the bard. Due to the peculiarity of the group, I chose to reinforce the signs, to repeat them, to multiply, to convey them through different sensorial channels. I don't know, we don't know a priori which proposal could fix in a unstable memory, which passage of the text could console a heart alone. We use the multiplicity of signs, voices, bodies, strong by the fact that we are an odd community and we want to integrate. For these reasons, the theatre language that respects us more is the togetherness, as an answer to an individuality that makes us more fragile and different than what we really are.

(from notes of direction by Alessandra Cortesi)

The theatre activities of "Gli amici di Luca" Are realised with the contribution





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



In the whole region hundreds of events, exhibitions, performances and meetings

www.emiliaromagnacreativa.it

Bologna | | Sunday 7th October - h 9.00/18.00

## Following the maps of awakenings ...

on little big footsteps: a long path of friendships and cooperations

#### **PROGRAM**

#### Casa dei Risvegli Luca De Nigris - Via Gaist 6 - Bologna

h. 9.00 To walk together: 20 years united in the heart of town.

Urban Trekking to discover the places of awakening and arrival under the Two Towers. In cooperation with "Trekking Italia Emilia-Romagna"

#### Via Rizzoli - Bologna

- h. 10.00 initiatives and awareness activities
- **h. 12.30** following the balloons flight (eco-friendly and biodegradable balloons) in presence of the authorities and of the testimonial Alessandro Bergonzoni
- h. 13.00 "Spaghetti bolognesi for charity", initiative promoted by the Committee for the Promotion of the original recipe of the Spaghetti Bolognese for the Luca De Nigris House of Awakenings
- h. 14.30 Short demonstrations of adapted sports:
  - Tai Chi Chuan workshops, Dance sport, fencing of wheelchair, adapted table-football









Some Italian towns will take part to the

Day of Awakenings on Coma research with different initiatives:

Gioia del Colle (BA), Pescara, Salerno, Caltagirone (CT), San Paolo Solbrito (AT), Agnone (IS), Cremona

During the morning

Philatelic Obliteration by Poste Italiane

On the sketch by Alessandro Bergonzoni



They grow, the years. They have, each year, roots and branches. They continue coming into the world, even just for a puff.
On the tree of winds.

(the tree of winds)

Alessandro Bergonzoni

#### In via Rizzoli with us

Thanks for their participation and cooperation

















#### Bologna | Wednesday 10th October - h. 2.00/6.00 p.m.

Casa dei Donatori di Sangue - Avis Provinciale - Via dell'Ospedale 20 - Bologna

Convention with the patronage

Ministero della Salute (Ministry of Health)

# Possibilities and limits of the return to driving after acquired brain damage

4 ECM credits have been conferred to this event for the following professions: doctors, physiotherapists, psychologists, occupational therapists

Among the activities of ordinary life, the return to driving represents one of the more desired rehab targets in the results of the different diseases (ictus, aneurism, brain injury, brain cancer) that may have involved the brain and the central nervous system. In fact, if the potential motor results can be more or less evident and, most likely, easier to compensate by using external aids, such as particular mirrors, handles, pedal adjustments, behavioural and cognitive results represent the most important obstacle to return to drive safely and with the right responsibility. Certainly this has heavy consequences in the life of these patients and their families, because the impossibility to drive reduces the participation in the social, productive and familiar activities. The idea of "not to have forgotten how to do it", is sufficient to have the certainty of being able to drive without putting themselves or the others in danger. This convention intends to reflect with the experts of the sector in a more suitable path of evaluation and a bigger awareness as regards to different problems about driving after Severe Acquired Brain Damage.

#### **PROGRAM**

Greetings from authorities

Introduce

Maria Vaccari president Gli amici di Luca

Gian Pietro Salvi president of La Rete, united associations for brain injury and GCA

Opening of works

Fulvio De Nigris director of the Study Centre for Coma Research, Gli amici di Luca

#### Reports:

#### "The activity of the commission Driving licences of Bologna"

Andrea Minarini director UOC Legal Medicine and Risk Management Azienda Usl di Bologna

#### "Introduction to the problem and revision of literature"

**Anna Mazzucchi** director of the Department for the Cure and the Rehabilitation of GCA Fondazione Don Gnocchi, Parma

#### "Evaluative modality, paths of complement and operative solutions"

Sonia Martelli psychologist, psychotherapist, Parma

## "The risk of incurring in road accidents in patients who resumed driving after a severe acquired brain damage"

Rita Formisano Head physician Post-Coma Unit Rehabilitation Hospital Fondazione Santa Lucia, Roma

#### "The return to safe driving after acquired brain damage: the proposal of a new path on the territory of Bologna"

Project Daily Workshops, Study Centre for Coma Research, Gli amici di Luca Anna Di Santantonio psychologist researcher Study Centre for Coma Research, Bologna Cristina Di Stefano psychologist researcher Study Centre for Coma Research, Bologna Elena Zavatta psychologist researcher Study Centre for Coma Research, Bologna

#### "Car accidents:

#### profiles of responsibilities of the disabled driver and damage compensation"

Eleonora Conforti lawyer studio legale Migliori-Torrella, Bologna

#### Moderators:

**Roberto Piperno** director UOC Rehabilitative Medicine and Neurorehabilitation Ospedale Maggiore, director of the Luca De Nigris House of Awakenings, Bologna

Matilde Leonardi Coma Research Centre-CRC of the Neurological Institute Foundation Besta, Milano

With the patronage

Organizational secretary: Gli amici di Luca Patrizia Boccuti - Info and registration: Tel. 051 6494570 - patriziab@amicidiluca.it



#### Belgium | Wednesday 12th December - h. 6.30 p.m.

University of Liège - Cité Miroir - Liège

#### What treatments after the coma?

Event program & speakers:

- h. 18.30 Welcome and introduction on disorders of consciousness (Pr Laureys)
- h. 18.45 Pharmacological treatments (Dr Gosseries)
- h. 19.10 Deep Brain Stimulation (Dr Lemaire)
- h. 19.30 tDCS and NIBS (Dr Thibaut)
- h. 19.50 Motricity (Dr Deltombe)
- h. 20.10 Round table with patient's families and associations and questions/anwers
- h. 20.45 concert

### Lithuania | Sunday 7th October - h. 10.00 a.m.

University of Siauliai - University Library - Vytauto str., 84 - Lithuania

## **Creating wellbeing together**

#### Event program:

- h. 10.00 Welcoming speeches by Rector of Siauliai University prof. dr. D. Jurgaitis, representative of Lithuanian Parliament dr. S. Tumėnas and Parson of Kairiai Parish priest licentiate R. Pranskaitis.
- h. 10.15 Modern approach to the disorders of consciousness and treatment strategies (neurologist A. Kazlauskas)
- h. 10.45 Problems of Social Inclusion of Awakenings through Labor Activities (lect. L. Miliuniene)
- h. 11.15 Issues of Long Life Learning of patients Awakening after Coma (lect. prof. L. Radzeviciene)
- h. 11.45 Challenges of Social Security in the Processes of Long-Term Rehabilitation (lect. I. Dobrovolskyte)
- h. 12.00 Coffee break
- h. 12.30 Round table discussions. Participants: specialists, parents and caregivers of patients awakening from coma.
- h. 13.30 Delfi group session for revealing the most actual problems for wellbeing of patients awakening from coma (moderator lect. E. Elijošius)
- h. 14.30 Concert of Siauliai University Student's Chorus "Studium"
- h. 15.00 End of the event

#### Cyprus | Saturday 13th October - h. 11.00 a.m.

Central Square of Lemesos - Lemesos

ESFC European Social Forum Cyprus

## To give dignity to patients after coma

Event program: greetings, reflections and march through the center of Lemesos speeches by the Mayor of Lemesos, the Minister of Health, of Presidents of the Cypriot network of non-governmental organizations



#### Denmark | From 24th to 26th October

University of Aalborg - Braga - Portugal

#### **International Conference ArtsIT and DLI 2018**

Anthony Brooks and Eva Irene Brooks, LUCAS project partner of the Danish University of Aalborg, they will participate as speakers in Braga (Portugal).

They will present the European Day of Awakenings at the International ArtsIT Conferences (7th EAI International Conference on Art, Interactivity & Games Creation) and DLI 2018 (3rd EAI International Conference on Design, Learning and Innovation) organized by the European Alliance for Innovation (EAI).



#### Spain | From 1st to 12th October

Nueva Opción - Calle Greses 21 - Valencia

Universidad Católica of València and Nueva Opción association that deals with GCA

#### Let's talk about coma

Event program:

- Workshop "the aspects of coma" Intervention of families of patients that have been in coma.
- Conference: "Coma and altered states of consciousness. The human side of the intervention", reports of health professionals from intensive care units and brain damage centres. Interventions by relatives of patients who have been in coma.
- Video: "Why the European Day of Awakenings": intervention of patients with acquired brain damage.



#### Portugal

#### **Novamente**

Support association for people with cranio-encephalic trauma and their families Initiatives to be defined













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