



# It's worth it!

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

#EUComaAwakeningsDay

#

EUROPEAN DAY OF AWAKENINGS

OCTOBER 7<sup>TH</sup> 2021

COMA AND ITS OUTCOMES



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 23<sup>th</sup> edition and it celebrates the 7<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 require now greater attention in order to make their rights and problems be visible and also their needs to be constantly and consciously identified by institutions in charge.

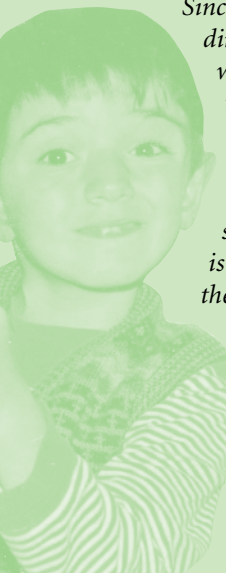
On October 7<sup>th</sup> the next “Day of awakenings” will deal with the above-mentioned issues and it will analyse social and clinical themes about research. This will be done through the social campaign and the celebration of our testimonial Alessandro Bergonzoni and two webinar conferences on “BIOETHICS AND THE FIVE SENSES” and the perspectives of the second “CONFERENCE ON CONSENSUS OF THE ASSOCIATIONS” that represent the relatives taking care of patients in coma, vegetative state, minimally conscious 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 “Elogio dell’amore”, (Praise of love), the outcome of theatre workshops 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 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 center 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 patients 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.



With the patronage



in cooperation with



European projects and partners



## GENERAL PROGRAM



**San Pellegrino Terme | Saturday, September 25<sup>th</sup>, 2021 - h. 9.00 a.m / 1.00 p.m.**  
*Hotel Bigio - Centro Congressi - Via Giacomo Matteotti, 2 - San Pellegrino Terme - Bergamo*

### 33° MEETING

## NEW TENDENCIES IN MEDICAL, NURSING AND REHABILITATION OF THE NEUROLOGICAL DISEASES

WITH THE PATRONAGE OF  
**Genesis Association**

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



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

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

CLOSE TO THE CELEBRATIONS FOR  
**SAN PETRONIO, PATRON SAINT OF BOLOGNA**



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

Once again in via Rizzoli, a street in Bologna, to attract interest of the public opinion on the themes of the outcome from coma and the recovery of social life after the recovery in the Casa dei Risvegli Luca De Nigris (Luca De Nigris House of Awakenings). This path sometimes discloses hard obstacles inside the family who accepts the patient with severe residual disabilities to face the new kind of life and to create different balances after the traumatic event. Awareness raising activities and recreational activities with CSI Centro Sportivo Italiano Comitato di Bologna (CSI, Italian Sport Centre, Bologna Committee).

**Bologna | Monday, October 4<sup>th</sup> - h. 3.30-5.00 p.m.**

*Giardino Casa dei Risvegli Luca De Nigris (The House of Awakenings Luca De Nigris Garden)*  
*Via Giulio Gaist, 6 - Bologna*

## THE NOISE OF SILENCE

**A pomegranate will be planted to remember who is no more.**



This initiative is a step of the “**Rumore del lutto**” (The sound of mourning) a cultural project born in Parma in 2007, from an idea of **Maria Angela Gelati** and **Marco Pipitone**, at its 15<sup>th</sup> Edition 2021. It has the ambition of identifying a new space for the dialogue and the reflection on life and death, through the inter-disciplinary and cross analysis among different scopes. During the initiative the statue “**Scienza e coscienza**” (Science and con-

science), realised by **Gennaro Natullo**, will be inaugurated. Readings of the theatre group “**Dopo...di nuovo, Gli amici di Luca**” (After...again, Friends of Luca). Initiative in cooperation with:



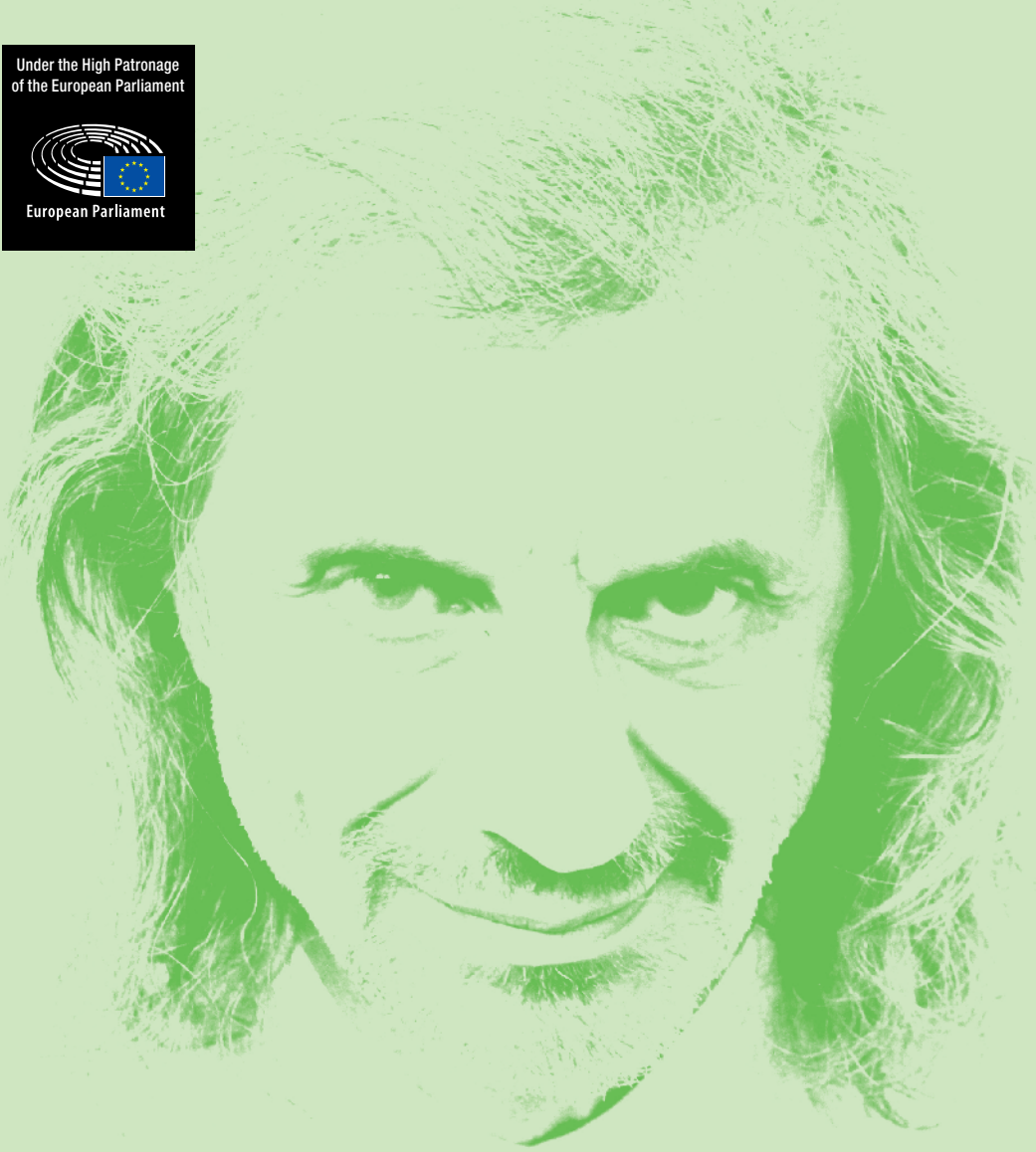
Unione  
 Buddhista  
 Italiana

Thanks to:



Under the High Patronage  
of the European Parliament

European Parliament


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

# to be or to be

October 7<sup>th</sup> 2021  
NATIONAL DAY OF  
AWAKENINGS 23<sup>rd</sup> edition  
ON COMA RESEARCH – IT'S WORTH IT  
EUROPEAN DAY OF  
AWAKENINGS 7<sup>th</sup> edition

 Bologna | Thursday, October 7<sup>th</sup> - h. 10.00-12.30 a.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



and



Since many years the traditional “Giornata Nazionale dei Risvegli” (National day of Awakenings) is a meeting opportunity to restate the necessity to see the differences, express solidarity, enjoy and celebrate together in a place of care linked to the town that reaffirm its normality with patients, families, operators and volunteers.

### PROGRAM

10.00 a.m.:

- Online connections with Italian and European cities taking part into the event
- **Presentation of the project ENNEADI** - European Network in Nutritional Education for Acquired Disabilities – co-financed by the European Union Erasmus+ program
- Readings and testimonies of patients who outcame coma and their families
- Meeting with representatives of institutions and authorities, with the participation of **Alessandro Bergonzoni**, testimonial of the Casa dei Risvegli Luca De Nigris (Luca De Nigris House of Awakenings)

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.



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

 Bologna | Thursday, October 7<sup>th</sup> - h. 9.00 p.m.

Teatro Dehon - Via Libia, 59 - Bologna

 gli amici di Luca

in cooperation with:

 TEATRO ARGINE

 DEHON.teatroaperto  
TEATRO STABILE DELL'EMILIA-ROMAGNA

present

## PRAISE OF LOVE

Deborah Fortini maker of the laboratory and author of the artistic project  
Martina Pittureri pedagogical coordination

Volunteers: Francesco Andreani, Giorgia Benini, Lorenzo Campeggi,  
Carmen Nubla, Marta Quitadamo, Marina Sfregoli

Thanks to the host structures Sant'Anna and Parco del Navile in Bologna  
and their educators Mariagrazia and Fabio.

To the families of our protagonists and in particular to  
Maurizio Mazzanti, always present with us.



Reservation required phone: 051 342934 (10 a.m.- 1 p.m., 3 p.m.-6 p.m)

Or by e-mail to: [biglietteria@teatrodehon.it](mailto:biglietteria@teatrodehon.it)

With the contribution of

 Regione Emilia-Romagna

Friends of Luca promote theatre workshops as a rehabilitation  
program at the Casa dei Risvegli Luca De Nigris  
(Luca De Nigris House of Awakenings)

 Diversissimi

 pon metro

 Comune di Bologna

 Agenzia per lo Sviluppo Territoriale

 UNIONE EUROPEA  
Fondi Strutturali e di Investimento Europei

 SCUOLE  
DI QUARTIERE

**Saturday, Oct. 9<sup>th</sup> and Sunday, Oct. 10<sup>th</sup>, 2021**

WEBINAR PROGRAM ON ZOOM PLATFORM


 la rete  
Associazione Italiana per il Trauma Cranico  
e la Great Commission Accademia

THE SECOND

 Federazione Nazionale  
Associazioni Trauma Cranico

# 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. Final event

 gli amici di Luca

With the patronage of

 Regione Emilia-Romagna

 Comune di Bologna

 ALMA MATER STUDIORUM  
UNIVERSITÀ DI BOLOGNA

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

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

 FNOMCeO

 FIASO  
Federazione Italiana  
Associazioni Trauma  
Cranico



Secretarial services: Patrizia Boccuti - [patriziab@amicidiluca.it](mailto:patriziab@amicidiluca.it)

partner  
 EXPOSANITA'  
ENERGIA CRASIS INNOVATION

 Bologna | Saturday, October 9<sup>th</sup> - h. 9.00 a.m / 6.0 p.m | Sunday, October 10<sup>th</sup> - h. 9.00 a.m / 1.00 p.m

WEBINAR ON ZOOM PLATFORM

## THE SECOND 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. Final event

**Saturday, October 9<sup>th</sup>, 2021**

8.45 a.m. Beginning of the conference

9.00 a.m. Greetings from the authorities

9.15 a.m.: presentation of the Committee

**Final relations of workgroup coordinators**

9.30 a.m. **Maria Teresa Angelillo** (Uniti per i risvegli association, Bari),

**Quality standards of care facilities in the postacute rehabilitative phase and in the chronic phase**

*Discussion*

10.30 a.m. **Lucia Lucca** (St. Anna Institute, Crotona)

**The networks and the model coma to community**

*Discussion*

11.30 a.m. **Elena Di Girolamo** (Rinascita e Vita association, Genova)

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

*Discussion*

12.30 a.m. **Anna Di Santantonio** (Gli amici di Luca association, Bologna)

**Coming back to work after ABI: definition for a model of a vocational, holistic and multidisciplinary rehabilitation,**

*Discussion*

1.30 p.m.: Break

*Resumption of work*

2.30 p.m. **Maria Grazia Inzaghi** (Quarenghi clinical institute, San Pellegrino Terme, Bergamo)

**Education, communication and narration programs for support to the family**

*Discussion*

3.30 p.m. **Ezio Torrella** (Torrella - Conforti law office, Bologna)

**The rights of patients with disabilities - legal protection and regulations**

*Discussion*

4.30 p.m. **Ivana Cannoni** (ATRACTO association, Montevarchi),

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

*Discussion*

5.30 p.m. **Fabio La Porta** (Casa Dei Risvegli House of Awakenings Luca De Nigris, Bologna)

**The Right to Research and the Development of the research**

*Discussion*

6.30 p.m.: conclusion of the work

Moderated by **Fulvio De Nigris** (Member of the Organizing Committee, President of the Committee and Director of the Study Center for Coma Research Gli amici di Luca, Bologna, Friends of Luca, Bologna)

**Sunday, October 10<sup>th</sup>, 2021**

9 a.m. - 1 p.m.: meeting of the representatives of the Committee

5.00 p.m.: presentation of the final document

info: [www.secondaconferenzaconsensoassociazioni.it](http://www.secondaconferenzaconsensoassociazioni.it)

Secretariat *Gli amici di Luca* - *Patrizia Boccuti* - Info and registrations:

Tel. 051 6494570 - [patriziab@amicidiluca.it](mailto:patriziab@amicidiluca.it)

 **Villamassargia | Thursday, October 14<sup>th</sup> - h. 5.00 p.m.**

Centro Famiglia - Piazza Pilar - Villamassargia - (SU)

PLUS DI IGLESIAS

Famiglia Famigliæ is a project proposed by the dall'Assessorato ai Servizi Sociali e dall'Assessorato Cultura del Comune di Villamassargia (The social service and Cultural Department of the Municipality of Villamassargia)

## FOR A NETWORK OF SERVICES AIMING AT PATIENTS WITH DISABILITIES

*Introduction*

For the Municipality of Villamassargia

The council member for Culture **Sara Cambula**:

The project Famiglia, Famigliæ - The council

member for Social Services **Marco Mandis**:

The cure beyond the patient

With the participation of **Francesco Sanna**,

RSA S. Elia di Nuxis

"I feel you are there: the experience of the Luca De Nigris House of Awakenings in the cure of patients with outcomes from coma and in support to their families."

**Fulvio De Nigris** Director of the study center on Coma Research, Gli amici di Luca, Bologna  
"Art therapy: puppets and puppet theatre as a narration and an incentive in the rehabilitation program"

**Mauro Sarzi** Human art - Le mani dei Sarzi, Cagliari (Sarzi's Hands, Cagliari)

*Conclusions*

**Debora Porrà** Mayor of the Municipality of Villamassargia

At the end of the meeting, the launch of ecological and biodegradable balloons with "Messages for an awakening".



 **Lithuania | Thursday, October 7<sup>th</sup> 2021***I<sup>a</sup> Part: University of Vilnius, Siauliai Academy, Center for education and rehabilitation Prof. Radviliškis**II<sup>a</sup> Part: Kurtuvėnai Regional Park, Parko g. 2 - Kurtuvėnai - reg. Siauliai - Lithuania***CREATING HEALTH AND WELLBEING TOGETHER**

Participants to the event: Specialists (Nutritionists, Speech Therapists, Physiotherapists, Occupational Therapists, Nurses, Professional Educators, Doctors, Tutors of these specialists) who work on the themes of nutrition with patients awakening from coma and their families; representative of the Lithuanian Parliament, representatives of the Municipality of Sauliai, representatives of the Public Health Office, representatives of the University of Vilnius Siauliai Academy, NGO that work with patients awakening after coma.

**PROGRAM OF THE EVENT***I<sup>a</sup> Part: Event at Vilnius University Siauliai Academy*

10.00 a.m. Welcome greetings from the Director of the University of Vilnius Siauliai Academy prof. doct I. Kaffemanienė, representative of Siauliai Public Health Office PhD.

Saulius Vaivada, Vice Mayor of the city of Siauliai Egidijus Elijusius, Parish Priest of Kairiai R. Pranskaitis.

11.00 a.m. Individual approach to Sport Activities and Healthy Nutrition (lect. L. Miliuniene).

11.20 a.m. Neuropsychological problems of nutrition (lect. Dr. I. Dobrovolskyte, R. Jadlauskienė).

11.40 a.m. Educational problems of the specialists working on the problems of nutrition with patients awakening from coma: sharing of good practices in member states of the EU (lect. prof. L. Radzeviciene).

12.00 a.m. Round table discussions.

*II<sup>a</sup> Part - Event at the Kurtuvėnai, Parko g. 2 Regional Park, Kurtuvėnai, reg. Siauliai, Lithuania*

1.00 p.m. Hippotherapy sessions. Outdoor sport activities (participants: - patients awakening from coma and their families, NGO specialists working with this target group, project team of the University of Vilnius, Siauliai Academy).

3.00 p.m. Tour - exploration “Diversity of the Landscape” (led by the representative of the Kurtuvėnai Regional Park) and barbecue party.

ore 18.00 End of the event.

 **Belgium | Saturday, September 25<sup>th</sup> 2021***Coma Science Group – University of Liege - Avenue de l'hôpital 11 - 4000 Liège - Belgio***CRS-R & SECONDS Online Workshop 2021**

Workshop for clinicians and researchers to learn about behavioural instruments available to evaluate patients with disorders of consciousness.- Coma Recovery Scale-Revised (CRS-R) e Short Evaluation of CONsciousness Disorders (SECONDS)

<https://www.eventbrite.be/e/crs-r-seconds-online-workshop-2021-tickets-166809588971>

 **Belgium | Thursday, October 7<sup>th</sup> 2021***Coma Science Group – University of Liege - Avenue de l'hôpital 11 - 4000 Liège - Belgio***CELEBRATION OF THE DAY OF AWAKENINGS**

Awareness measures and participation to the work group to prepare the Second World Coma Day (WCD) on March 22<sup>nd</sup>, 2022

<https://www.curingcoma.org/events2/world-coma-day>

 **Denmark | Thursday, October 7<sup>th</sup> 2021***Aalborg University- Fredrik Bajers Vej 5 - Aalborg - Denmark***CELEBRATION OF THE EUROPEAN DAY OF AWAKENINGS**

Proclamation of the day to the research group Aalborg University- L-ILD - IT and Learning Design - Xlab: Design, Learning and Innovation - The Center for Applied Game Research.

 **Denmark | Thursday, December 2<sup>nd</sup> 2021 and Friday 3 December 3<sup>rd</sup> 2021***Aalborg University- Fredrik Bajers Vej 5 - Aalborg - Denmark***In cooperation with Halmstad University - SWEDEN**

The theme of the European Day of Awakenings will be presented during the 6<sup>th</sup> EAI International Conference on Design, Learning & Innovation (DLI 2021). This year DLI invites critical, innovative and transdisciplinary perspectives on the theme: “Moving borders to discover new and emerging means and technologies to realize needs, ideas and human desires”.

 **Spain | Thursday, October 7<sup>th</sup> 2021***Nueva Opción - Asociación de Daño Cerebral Adquirido de la Provincia de Valencia - Calle Greses 21 - València***CELEBRATION OF THE EUROPEAN DAY OF AWAKENINGS**

Animated Gif on social network and awareness activities on the media

 **Spain | Thursday, October 7<sup>th</sup> 2021***University of València – Department of Social Services - València***SEMINAR - SOCIAL CARE FOR PATIENTS WITH ACQUIRED BRAIN INJURIES AND THEIR FAMILIES** **Spain | Saturday, October 23<sup>th</sup> 2021***Parque del Río Turia - Parco fluviale del Turia - València***CELEBRATION OF THE ACQUIRED BRAIN INJURIES (ABI) IN SPAIN** **Spain | Tuesday, October 26<sup>th</sup> 2021***Plaza del Ayuntamiento de Valencia (City Council square) - València***NATIONAL DAY OF ACQUIRED BRAIN INJURIES (ABI)**

Information chart on ABI and coma.

Lighting of the monuments of Valencia and Xàtiva (Valencia), Ayuntamiento de Valencia (Valencia City Hall), Puerta de la Mar, Palacio de las Artes-Ciudad de las Ciencias (Art Palace-City of Science), Ayuntamiento de Xàtiva (Xàtiva City Hall) in ABI colour (blue)

 **Portugal | Thursday, October 7<sup>th</sup> 2021***NOVAMENTE, Associação Apoio aos Traumatizados Crânio-Encefálicos e Suas Famílias - Largo do Colégio nº 5 2750-324 Cascais - Avenida de Infante Sagres 349 4405-565 Valadares - Vila Nova de Gai***CELEBRATION OF THE NATIONAL DAY OF AWAKENINGS**

Testimonials (videos, images and texts) on social networks, to create awareness on the theme.

the National Day of Awakenings is supported by



CLUB L'INGUARIBILE  
VOGLIA DI VIVERE



media partner



Thanks to Claudia Romagnoli for the English version