

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS
22nd Annual Meeting
Tuesday and Wednesday, 2-3 December 2014
Brussels, Belgium

An Exciting Year for ALS Awareness in Italy

Christian Lunetta - Maurizio Colombo





Aisla onlus: People Helping People

In Italy, 2014 will be remembered as an exciting year for awareness regarding ALS.

The AISLA's choice was to run important communication activities aimed to increase the knowledge of disease and of daily activities of the Association.



Aisla onlus: People Helping People



The campaign aims to raise public awareness on the donation of "5 x mille" to AISLA and " *donating* - as suggested by Enzo Bianchi, the prior of the monastic community of Bose - *there is a subject, the donor, who in freedom, not forced, and in generosity, in love, makes a gift to another, regardless of its response.*"

Aisla onlus: People Helping People



CONTRO LA SLA E LA SCLEROSI MULTIPLA CI VUOLE ARMONIA

CONTRIBUISCI ANCHE TU ALLA LOTTA CONTRO LA SLA E LA SCLEROSI MULTIPLA:
ACQUISTA IL BRANO "UN AMORE COSÌ GRANDE 2014" OPPURE DONA INVIANDO UN SMS
O CHIAMANDO DA RETE FISSA IL NUMERO SOLIDALE

45502 DAL 30 MAGGIO
AL 10 GIUGNO



Dona **2 euro** con SMS da cellulare personale
TIM VODAFONE WIND 3 POSTEMOBILE COOPVOCE NOVERCA

Dona **2 euro** con chiamata da rete fissa TELETU TWT

Dona **2 o 5 euro** con chiamata da rete fissa TELECOM ITALIA FASTWEB



negram.ro
UN AMORE COSÌ GRANDE 2014



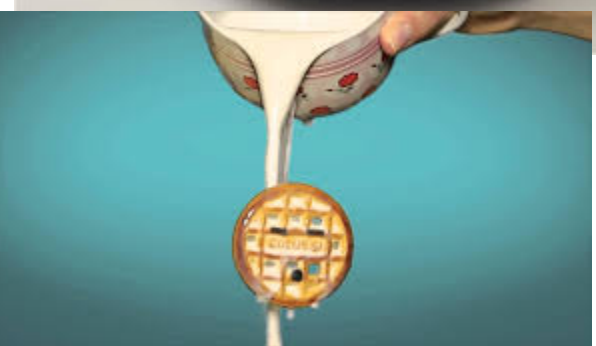
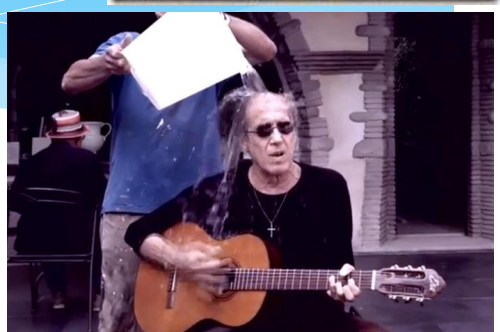
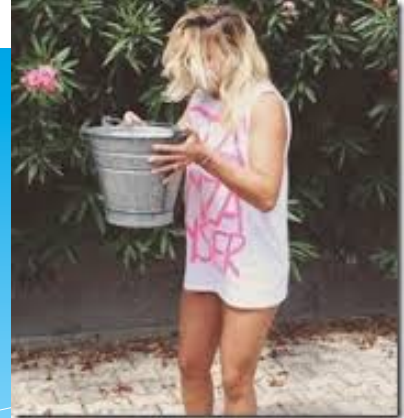
Disponibile su
iTunes





The ALS ICE BUCKET CHALLENGE

Does It Matter HOW You Participate?



#A SOCI@L CAMPAIGN

Aisla web site

- * 50,000 unique users per day during the campaign
- * 300,000 users in a month (280,000 users is the total of the previous 12 months)
- * 900,000 pages visited on the site

FACEBOOK

- * Over 10,000 "I Like it" in August (against the previous 3,000).
- * An average of 80,000 users for every our post, with peaks of over 126,000 users to post reached between August 24th and 26th.

TWITTER

- * 31 390 views of our tweets,
- * Many tweets were quoted by TV broadcasts as a source of information
- * In August the number of our followers grew up from 700 to 2700

#Icebucketchallenge

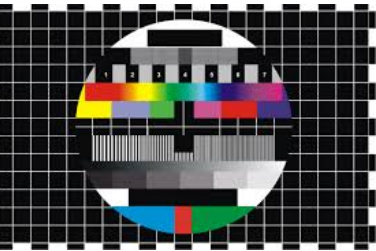


Grazie a tutti per la fiducia!
Ora l'obiettivo è raccogliere 2 milioni di euro per la ricerca.
Dona qui: <http://bit.ly/Dona-Aisla>

aisla ONLUS
ASSOCIAZIONE ITALIANA
SCLEROSI LATERALE AMIOTROFICA



SOCC
relazioni pubbliche
e istituzionali



- 690 articles on newspapers and websites
- 270 Italian television and radio broadcasts on «Ice Bucket Challenge» campaign



#Icebucketchallenge
**GRAZIE AD OGNUNO DI VOI
ABBIAMO RAGGIUNTO
2.000.000 di €**



49 ALS/MND Alliance @ALSMNDAlliance · 3 h · ... Altro
Congrats @aislaonlus, our members in Italy! They've raised €800k through #IceBucketChallenge. On the way to €1m! pic.twitter.com/BZWvpJ59Qn

#icebucketchallenge

DA SFIDA NASCE SFIDA

aiutateci a raggiungere 1 milione di euro
entro il 21 settembre 2014
giornata nazionale contro la SLA



ASSOCIAZIONE ITALIANA
SCLEROSI LATERALE AMIOTROFICA

AIM #1: «Operazione sollievo» or relief operation

This operation includes:

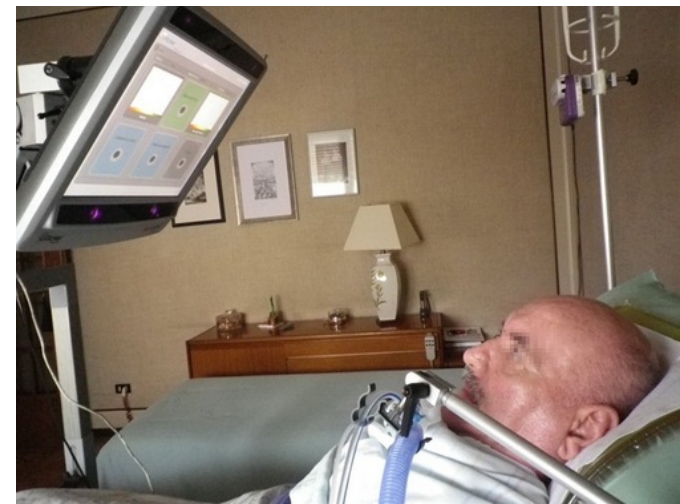
- ✓ Economic contributions to the families of PALS who face a difficult period
- ✓ Financial supports for the families to have an additional caregiver to ensure night and day assistance for PALS
- ✓ To guarantee a multidisciplinary consulting at home for PALS
- ✓ To buy or rent the necessary tools for home care of PALS (lifters, anti-bedsores mattresses, wheelchairs, communicators, etc.)
- ✓ Legal support for PALS

21 SETTEMBRE 2014
GIORNATA NAZIONALE
SLA



UN CONTRIBUTO
VERSATO CON GUSTO.

Cerca i gazebo di AISLA nelle piazze di tutta Italia
su www.aisla.it



AIM #2: Italian ALS Biobank

AISLA will realize the first National Biobank for ALS to provide the DNA samples and cells obtained from PALS to the network of all Italian Researchers



AIM #3: ARISLA (Italian Research Agency for ALS)



Per un futuro senza SLA

AGENZIA DI RICERCA PER LA SCLEROSI LATERALE AMIOTROFICA



AIM #3: ARISLA (Italian Research Agency for ALS)



€ 2.137.000

Nr	Title	PI	euro	Type of research
1	ARCI , RNA circuitries in Amiotrophic Lateral Sclerosis pathogenesis	Irene Bozzoni , Univ. degli Studi di Roma "La Sapienza"	240.000,00	Basic, Full Grant
2	CARDI NALS , Cardiovascular Neural Regulation In Amyotrophic Lateral Sclerosis	Laura Dalla Vecchia , Fondazione Salvatore Maugeri IRCCS, Milano	121.00,00	Clinical, Full Grant
3	CHRONOS , Chronic and Sporadic Mechanisms of TDP-43 Dysfunction	Fabian Feiguin , International Centre For Genetic Engineering And Biotechnology (ICGEB), Trieste	170.100,00	Basic, Full Grant
4	CONNECTALS , Network degeneration in motor neuron diseases (MND): a study of the structural and functional connectomes in Amyotrophic Lateral Sclerosis and other MND	Massimo Filippi , Fondazione Centro San Raffaele, Milano	300.000,00	Clinical, Full Grant
5	GRANULOPATHY , VCP and autophagolysosomal pathway: guardians of proteostasis and stress granule dynamics. Unraveling their applications in ALS	Serena Carra , Univ. degli Studi di Modena e Reggio Emilia	299.585,00	Basic, Full Grant
6	PATH-FOR-ALS , P2X7 as a target for Amyotrophic Lateral Sclerosis	Cinzia Volontè , Istituto di Biologia Cellulare e Neurobiologia, CNR, Roma	147.000,00	Translational, Full Grant
7	GF_ALS , Genetic engineering to produce new proteins for the protection of MN in ALS	Ermanno Gherardi , Univ. degli Studi di Pavia	172.370,00	Translational, Pilot Grant
8	smallRNALS , The role of dysregulation of small RNAs and proteomic analysis of patient-derived induced pluripotent stem cells	Stefania Corti , Univ. degli Studi di Milano	300.00,00	Basic, Full Grant

AIM #3: ARISLA (Italian Research Agency for ALS)



€ 2.137.000

Nr	Title	PI	euro	Type of research
1	ALSHDCA1 , HDAC-1 TDP-43 interaction: implication for ALS	Claudia Crosio , Univ. degli Studi di Sassari	60.000,00	Basic, Pilot Grant
2	CONSLA , Setting Of A new pre-Conditioning Model for Amyotrophic Lateral Sclerosis	Giuseppe Pignataro , Univ. degli Studi di Napoli "Federico II"	44.992,50	Basic, Pilot Grant
3	DC-ALS , Activation state and Functionality of Dendritic cells from peripheral blood of ALS patients	Francesca Granucci , Univ. degli Studi di Milano-Bicocca	50.000,00	Basic, Pilot Grant
4	EX ALTA , EXploring the peripheral nervous system path to unravel Amyotrophic LaTerAl sclerosis	Angelo Quattrini , Fondazione Centro San Raffaele	56.000,00	Translational, Pilot Grant
5	EpiALS Study of the role of epigenetic regulators in the pathogenesis of ALS	Camilla Bernardini , Univ. Cattolica del Sacro Cuore	60.000,00	Basic, Pilot Grant
6	FUSMALS , Functional Interaction of FUS with SMN as A Common Pathogenic Pathway For Motor Neuron Diseases	Mauro Cozzolino , Istituto di Farmacologia Traslazionale, CNR, Roma	59.955,00	Basic, Full Grant
7	MAMMALS , MiRNAs as Microglia Modifiers for ALS	Chiara Parisi , Istituto di Biologia Cellulare e Neurobiologia, CNR, Roma	56.000,00	Basic, Pilot Grant

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THERAPEUTIC CHOICES OF PERSON WITH ALS Consensus Document of AISLA Medical-Scientific Commission



LE SCELTE TERAPEUTICHE DELLA PERSONA AFFETTA DA SLA

DOCUMENTO DI CONSENSO
DELLA COMMISSIONE MEDICO SCIENTIFICA
DI AISLA ONLUS

Working group

•AISLA medical-scientific commission

- Neurologist: Mario Sabatelli, Adriano Chiò, Claudia Caponnetto, Christian Lunetta, Jessica Mandrioli, Maria Rosaria Monsurrò, Paolo Volanti, Letizia Mazzini, Nicola Ticozzi, Gabriele Mora, Ettore Beghi, Giuseppe Borghero
- Pulmunologist: Michele Vitacca
- Physiatrist: Nadia Cellotto
- Genetist: Gabriella Restagno, Francesca Luisa Conforti
- Biologist: Caterina Bendotti, Maria Teresa Carri
- PALS: Mario Melazzini

•Consultant:

- Prof. Penasa - Constitutionalist, University of Trento
- Dr. Olivieri - Anesthetist, Novara Hospital
- Prof. Barbisan - Bioethicist, University of Padova
- Prof. Spagnolo - Bioethicist, Cattolica University Rome

•**Coordinator**: Dr. Daniela Cattaneo, Palliative care specialist

Only a life lived in the service to others is worth living
Albert Einstein
(14 March 1879 - 18 April 1955)

