An Exciting Year for ALS Awareness in Italy
Christian Lunetta - Maurizio Colombo
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.
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."*
CONTRO LA SLA E LA SCLEROSI MULTIPLA
CI VUOLE ARMONIA

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

45502 DAI 30 MAGGIO AL 10 GIUGNO

Dono 2 euro con SMS da cellulare personale
TIM VODAFONE WIND 3 POSTEMOBILE COOPVOCO NOVERCA
Dono 2 euro con chiamata da rete fissa TELETU TWT
Dono 2 o 5 euro con chiamata da rete fissa TELECOM ITALIA FASTWEB

negram ro
UN AMORE COSÍ GRANDE 2014
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**

* 31390 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
- 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 €.
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-bedsore mattresses, wheelchairs, communicators, etc.)
- Legal support for PALS
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)

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<thead>
<tr>
<th>Nr</th>
<th>Title</th>
<th>PI</th>
<th>euro</th>
<th>Type of research</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>ARCI, RNA circuitries in Amiotrophic Lateral Sclerosis pathogenesis</td>
<td>Irene Bozzoni, Univ. degli Studi di Roma “La Sapienza”</td>
<td>240,000,00</td>
<td>Basic, Full Grant</td>
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<tr>
<td>2</td>
<td>CARDI NALS, Cardiovascular Neural Regulation In Amyotrophic Lateral Sclerosis</td>
<td>Laura Dalla Vecchia, Fondazione Salvatore Maugeri IRCCS, Milano</td>
<td>121,00,00</td>
<td>Clinical, Full Grant</td>
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<td>3</td>
<td>CHRONOS, Chronic and Sporadic Mechanisms of TDP-43 Dysfunction</td>
<td>Fabian Feiguin, International Centre For Genetic Engineering And Biotechnology (ICGEB), Trieste</td>
<td>170,100,00</td>
<td>Basic, Full Grant</td>
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<td>4</td>
<td>CONNECTALS, Network degeneration in motor neuron diseases (MND): a study of the structural and functional connectomes in Amyotrophic Lateral Sclerosis and other MND</td>
<td>Massimo Filippi, Fondazione Centro San Raffaele, Milano</td>
<td>300,000,00</td>
<td>Clinical, Full Grant</td>
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<td>5</td>
<td>GRANULOPATHY, VCP and autophagolysosomal pathway: guardians of proteostasis and stress granule dynamics. Unraveling their applications in ALS</td>
<td>Serena Carra, Univ. degli Studi di Modena e Reggio Emilia</td>
<td>299,585,00</td>
<td>Basic, Full Grant</td>
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<td>6</td>
<td>PATH-FOR-ALS, P2X7 as a target for Amyotrophic Lateral Sclerosis</td>
<td>Cinzia Volontè, Istituto di Biologia Cellulare e Neurobiologia, CNR, Roma</td>
<td>147,00,00</td>
<td>Translational, Full Grant</td>
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<td>7</td>
<td>GF_ALS, Genetic engineering to produce new proteins for the protection of MN in ALS</td>
<td>Ermanno Gherardi, Univ. degli Studi di Pavia</td>
<td>172,370,00</td>
<td>Translation, Pilot Grant</td>
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<td>8</td>
<td>smallRNALS, The role of dysregulation of small RNAs and proteomic analysis of patient-derived induced pluripotent stem cells</td>
<td>Stefania Corti, Univ. degli Studi di Milano</td>
<td>300,00,00</td>
<td>Basic, Full Grant</td>
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<td>1</td>
<td>ALSHDCA1, HDAC-1 TDP-43 interaction: implication for ALS</td>
<td>Claudia Crosio, Univ. degli Studi di Sassari</td>
<td>60.000,00</td>
<td>Basic, Pilot Grant</td>
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<td>2</td>
<td>CONSLA, Setting Of A new pre-Conditioning Model for Amyotrophic Lateral Sclerosis</td>
<td>Giuseppe Pignataro, Univ. degli Studi di Napoli “Federico II”</td>
<td>44.992,50</td>
<td>Basic, Pilot Grant</td>
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<td>3</td>
<td>DC-ALS, Activation state and Functionality of Dendritic cells from peripheral blood of ALS patients</td>
<td>Francesca Granucci, Univ. degli Studi di Milano-Bicocca</td>
<td>50.000,00</td>
<td>Basic, Pilot Grant</td>
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<td>4</td>
<td>EX ALTA, EXploring the peripheral nervous system path to unravel Amyotrophic LaTerAl sclerosis</td>
<td>Angelo Quattrini, Fondazione Centro San Raffaele</td>
<td>56.000,00</td>
<td>Translational, Pilot Grant</td>
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<td>5</td>
<td>EpiALS, Study of the role of epigenetic regulators in the pathogenesis of ALS</td>
<td>Camilla Bernardini, Univ. Cattolica del Sacro Cuore</td>
<td>60.000,00</td>
<td>Basic, Pilot Grant</td>
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<td>6</td>
<td>FUSMALS, Functional Interaction of FUS with SMN as A Common Pathogenic Pathway For Motor Neuron Diseases</td>
<td>Mauro Cozzolino, Istituto di Farmacologia Traslazionale, CNR, Roma</td>
<td>59.955,00</td>
<td>Basic, Full Grant</td>
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<td>7</td>
<td>MAMMALS, MiRNAs as Microglia Modifiers for ALS</td>
<td>Chiara Parisi, Istituto di Biologia Cellulare e Neurobiologia, CNR, Roma</td>
<td>56.000,00</td>
<td>Basic, Pilot Grant</td>
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Aisla onlus: People Helping People

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

Working group

• AISLA medical-scientific commission
  o 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
  o Pulmonologist: Michele Vitacca
  o Physiatrist: Nadia Cellotto
  o Genetist: Gabriella Restagno, Francesca Luisa Conforti
  o Biologist: Caterina Bendotti, Maria Teresa Carri
  o PALS: Mario Melazzini

• Consultant:
  o Prof. Penasa - Constitutionalist, University of Trento
  o Dr. Olivieri - Anesthetist, Novara Hospital
  o Prof. Barbisan - Bioethicist, University of Padova
  o 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)