

## Overview of activities: 1<sup>st</sup> European Narcolepsy Day, March 18, 2010

Country	Name of main local contact(s)	Main Activities 2010
Austria	Birgit Högl	Local manifestations
Belgium	Dirk Pevernagie, Robert Poirrier, Sebastiaan Overeem	Local manifestations
Brazil	Flávio Alóe, Geraldo Rizzo	Press release, press conference, broadcasting of Alice and Narcolepsy cartoon in local TV
Croatia	Zoran Dogas	Public lecture and round table (during Brain Awareness Week 2010), press release, tv/radio
Czech Republic	Karel Sonka, Sona Nevšimalová	Cartoon Alice and Narcolepsy will be presented on press conference linked to 1 <sup>st</sup> European Narcolepsy Day and World Sleep Day. 45 minutes program in TV (patients' stories, discussion, short view in sleep lab, etc), with cartoon broadcasting too.
Denmark	Poul Jennum	Scientific Symposium in Lugano. Press release and conference, 2 days meeting patients, video via patients' organization
Finland	Markku Partinen	Press release, presentations in local meetings in different hospitals run by child neurologists. 28.3-3.4.: official "Vigilance Week". Cartoon Alice and Narcolepsy shown in local meetings. Symposium for neurologists of Southern Finland about evaluation of sleepiness and narcolepsy (MP). Articles about narcolepsy in the Finnish Sleep Federation newsletter.
France	Yves Dauvilliers, Damien Leger, Philippe Peigneux, Pierre Philip	National sleep day in 50 sleep centers organized by the "Institut du Sommeil et de la Vigilance". Day of Narcolepsy included in this manifestation. For Hotel Dieu Sleep Center, a sleep village on the Place de l'Hôtel de Ville in Paris with press conference and several focuses will be established during the day. One on narcolepsy with the help of our rare disease hypersomnia center. French version of Alice and Narcolepsy cartoon will be broadcasted on TV. Website <a href="http://www.je-dors-trop.fr">www.je-dors-trop.fr</a> .
Germany	Dirk Hermann, Ulf Kallweit, Geert Mayer, Wolfgang Oertel, Thomas Pollmächer, Thomas Penzel, Peter Geisler	Local manifestations
Greece	Nikolas-Tiberio Economou, Periklis Ktonas, Constantin R. Soldatos	Press release/conference, TV info, Alice and Narcolepsy cartoon in greek/video broadcasting (all during the whole week), 2 booklets/ flyers.
Hungary	Zoltán Szakács	Press release, press conference on narcolepsy and the world sleep day (organized by the Hungarian Sleep Society, contact with national TV channels and important newspapers, symposia for MD (credit course about EDS for neurologist, child neurologist and GP. Start to establish the Hungarian narcolepsy patient group on the occasion of this event.
Israel	Peretz Lavie	Local manifestations
Italy	Luigi Ferini-Strambi, Raffaele Ferri, Giuseppe Plazzi, Fabio Pizza	Scientific symposium in Lugano. Press release through the Italian Narcolepsy Association(web site <a href="http://www.narcolessia.it">www.narcolessia.it</a> ) based on the material produced in the previous years and launching a new awareness campaign with "Lupo Alberto" cartoon.

		Patients' meeting in Bologna. Press Release on the hot topics of narcolepsy. New media campaign with Lupo Alberto Cartoon ( <a href="http://www.narcolessia.it/">http://www.narcolessia.it/</a> ). Facebook group link <a href="http://www.facebook.com/?ref=home#!/group.php?gid=316035311023">http://www.facebook.com/?ref=home#!/group.php?gid=316035311023</a>
Lithuania	Vanda Liesiene, Sapiega Hospital	Press release, press conference on local TV/radio. Scientific symposia. Swiss Alice and Narcolepsy cartoon will be sent to Child Neurologists, to be shown on local meetings
Montenegro	Slavica Vujisic, Ljiljana Radulovic	Press release, meeting patients. Presence in morning program at national TV (talk about Narcolepsy) as well as talk at Clinical center
Netherlands	Claire Donjacour , Gert Jan Lammers	Participation in Scientific Symposium in Lugano, press release, broadcasting of Alice and Narcolepsy cartoon in dutch on local TV, Youtube and gmail.com accounts. YouTube username:EUNNnl . Google Account email address:EUNNnl@gmail.com
Norway	Per Egil Hesla, Michael Lensing	Broadcast information on local TV. Scientific program including seminar at the local hospital. Information desk in "Paradestrasse Oslo". Co-operation with patients' organizations, state health organization and Oslo University Hospital, Ullevål. Motto 2010 "Children and adolescents with narcolepsy - do they exist?" Expected Norwegian version of Alice and Narcolepsy.
Portugal	Marta Gonçalves, Teresa Paiva	Press release, press conference, information TV/radio high media involvement including patients' testimonies. Portuguese flyer for patients. Expected Portuguese version of Alice and Narcolepsy Cartoon, to be presented on ESSR congress in Lisbon.
Romania	Stefan Mihaicuta	Local manifestations
Russia	Alexander Kalinkin, Vladimir M. Kovalzon	Scientific Symposia. Information via National Sleep Society. <a href="http://www.sleep.ru">www.sleep.ru</a> Expected Russian version of Alice and Narcolepsy Cartoon.
Serbia	Slavko Jankovic, Zoran Martinovic	Lecture on narcolepsy at the Institute of Neurology. Article in local press. 1 hour broadcasting on Art channel in February, commenting on narcolepsy and sleep diseases in general. Via Media Center of the Belgrade Clinical Center, organization of a short TV broadcasting to comment on narcolepsy.
Slovenia	Leja Dolenc, Maja Vovk	Press release, press conference, local meetings with patients, scientific symposia, patients' brochure, local book for GP's, neurologists and medical students, broadcasting of Alice and Narcolepsy Cartoon in English with subtitles.
Spain	Rosa Pereita, Joan Santamaria, Javier Puertas, Alex Iranzo	Organized by Spanish Sleep Society. Documentaries about sleep disorders on Odissey channel, information about narcolepsy and sleep disorders in Europe and Spain in press release. On march 18th, extended information on public Spanish TV. Contact and extended informations to local tv/press by "Asociación Española de Narcolepsia" (AEN), <a href="http://www.narcolepsia.org">www.narcolepsia.org</a> . On line interview on Revista de Neurología with European experts .
Sweden	Ludger Grote, Lena Leissner	Local manifestations
Switzerland	Claudio Bassetti, Monika Raimondi, Fiammetta Bornatico, Ramin Khatami, Johannes Mathis, Esther Werth, Andrea Rossetti, Mehdi Tafti, Thomas C. Wetter, Stanley Zagury, Christian	Scientific symposium in Lugano for 3 <sup>rd</sup> Swiss Narcolepsy Day. Creation in Lugano of Alice and Narcolepsy cartoon in Italian/English, German,French, Spanish and it's diffusion to all countries participating. Creation of Narcolepsy and Art booklet sent to all Narcolepsy Day participants. Creation of Swiss Italian Patients' association with patients' flyer in Italian.

	Baumann, Rositsa Poryazova Neumann, Barbara Tettenborn	Local manifestations in Lugano, Bern, Zurich, St. Gallen, Lausanne and other regions, including broadcasting on local TV's of Alice and Narcolepsy Cartoon in national languages, patients' meetings. Presentation in local tv (cartoon, patients' testimonies, interview with experts) and local press. YouTube-login:EUNNch E-mail address for Google-account:EUNNch@gmail.com
Turkey	Derya Karadeniz	Turkish Sleep Medicine Society prepared posters about Narcolepsy send to all hospitals to make awareness of both medical staff and also the public coming to hospitals for any reason. The advertisement on 18h March in local press/radio. The information about narcolepsy will be shown, included Alice and Narcolepsy Cartoon on main national TV
U.K.	John M. Shneerson	Local manifestations, press and TV release.