

The European Newsletter

of (ex-) Users and Survivors of Psychiatry

March 2002

The Newsletter of The European Network of (Ex-)Users and Survivors of Psychiatry

ENUSP-Coordinator / Desk

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The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.

SPRING 2002 EDITORIAL

Why “spring”? Certainly not because we merely wish to apologize for the delay in the issuing of the Newsletter. Instead, we would like to emphasise that this season should continue successfully without apologies and excuses of any sort. They have been too frequent in the past.

The editing, printing and distributing of the European Network only official bulletin have encountered numerous problems for the past two years, including those of financial nature, but we do hope that some of the most burning questions have been solved. We are lucky to operate a good quality computer with a fairly efficient printer thus the Newsletter gains colour. The ENUSP of course maintains its link with the Internet, which means that you are still able to directly take part in creating our visions, standpoints and opinions, or simply to deliver any interesting news from your countries.

By the way, you are invited to <http://www.enusp.org>. See our latest website there. Admire it. Criticise it. Enlarge it. Make our visage more complete and attractive.

We do not expect the next edition of the Newsletter sooner than in the summer 2002. Your correspondence will always be helpful, anyway, also in order for us to take your corrections into consideration, to make your comments heard and, simply, to snowball them.

At the same time, in its regular meetings the ENUSP Board deals with a vast number of topics – see the following pages of the Newsletter and our home website. The countries/organisations we think have no access to the website will be supplied with the Newsletter by mail. By our estimates we have to produce and send no less than 250 copies, including some for the members

of the European Network from Central and Eastern Europe.
All the copies are free of charge.

List of European self-help, (ex-)users/survivors- and user-orientated organisations

The new (interim) secretary Peter Lehmann, who was ENUSP-webmaster already, leads a list of many addresses, which are worthful for (ex-)users and survivors of psychiatry and their friends. On the list you can find the ENUSP-members too. With the current grant of the European Commission now there is a very good chance to complete, correct and enhance this list. Peter asks you kindly to send him all necessary information: address-changes, phone, fax, e-mail-address, web-address, and a short description of the organisation in English and your home-language. If you do not have an internet-website for your own, there is the possibility, that Peter makes one for you; if you send him the material per e-mail or post (but then it has to be type-written, no hand-written remarks), you can add up to two pictures. Please do not send a fax. If you have internet-access, see the special page of the Dutch group [Werkgroep Stap](#); so your website in the frame of the ENUSP-website could look like.

- * [Forum Anti-Psychiatrischer Initiativen \(FAPI\) Wien](#): FAPI Vienna pleads for abolition of involuntary treatment and protection of the rights of (ex-)users and survivors of psychiatry; a further concern of the group is the promotion of alternatives to psychiatry. [FAPI Wien setzt sich für die Abschaffung der Zwangsbehandlung und den Schutz der Rechte Psychiatriebetroffener ein; ein weiteres Anliegen der Gruppe ist die Förderung von Alternativen zur Psychiatrie.] Address: FAPI Wien, Donaustadtstr. 1/101, A-1220 Wien. Tel.: +43-(0)1-9226494 (Yolanda Tillner), Fax +43-(0)1-2639596. E-mail: fapi@everymail.net
- * "Freiräume" (ARGE – Exit sozial Linz), Petrusg. 8/5, A-1030 WIEN
- [Netzwerk Spinnen](#), Ottensheimerstraße 96/2, A-4040 LINZ, Tel. & Fax: +43-(0)732-700924, E-mail: office@nesp.cc. Ein ganzheitlicher Behandlungsansatz, Qualitätskontrolle in psychosozialen Einrichtungen, Integration von Betroffenen sind ein Teil der Ziele von netzwerk spinnen, der Interessensvertretung von Psychiatrieerfahrenen in Oberösterreich.
- Strada Pro Mente, Goethestr. 22, A-4020 LINZ
- Kuckucknest, Harald Hofer, Grimmsgasse 40/5, 1150 WIEN
- Omnibus: Gruppe Vorarlberger Psychiatrie- und Psychose-Erfahrener. Tätigkeit: Selbsthilfe, Empowerment, Psychoseseminar. "Dialog-Gespräch" jeden zweiten Dienstag im Monat, um 19 Uhr in Dornbirn, Club Antenne, Moosmahlstr. 4. Beratungstelefon: 0663-9537935. Vereinsmitglieder treffen sich jeden letzten Dienstag im Monat, 18.30 bis 20.00 ebenfalls im Club Antenne. Anmeldung: 0663-9537935 oder 05572-41357. Kontakt: Michael Chmela, Baumgarten 18, A-6858 Bildstein. E-mail: omnibus.beratung@vol.at
- Beratungsstelle "Gleiche beraten Gleiche", Anton-Schneider-Str. 21, A-6900 Bregenz, E-mail: omnibus.beratung@vol.at

Azerbaijan

- Caspian Mental Health Ass., H. Haciev st. 42-11, BAKU

Belarus

- * Minsk Initiative Group, BUSPW, Ul. V. Khoruzhaya 16-161, MINSK 220123

Belgium

- * Uilenspiegel. De v.z.w. Uilenspiegel werkt ten behoeve van de gebruikers van Geestelijke Gezondheidszorg aan informatie van het publiek, aan belangenbehartiging van de patiënten, geeft ook juridisch en psychosociaal advies. Address: Berckmansstraat 52, 1060 BRUSSEL. Phone: +32-(0)2-5393925, Fax: +32-(0)2-5394522, E-mail: VZW_uilenspiegel@vt4.net

- * Kisjot Ombud Services, Goudstraat 8, 9000 GENT
- * Together, Chaussée Brunehault 268, 4041 VOTTEM
- Flemish Survivors Movement, Postbus 48, BERCHEM 5

Bosnia and Herzegovina

- * Bosnian Anti-Trauma-Federation. 7 groups, about 400 members, mainly users/survivors (Union of Societies for Mental Health in Mental Misery), Sarajevo, Skenderija 72, 71000 Sarajevo, Phone +378 33 444536, Fax +387 36 577090, E-mail: behar@cob.net.ba

Bulgaria

- * Mercy, Mramor Blvd Block 4, 3500 BERKOVITZA
- Mental Health Society of Sofia, Social Psychiatry Unit University Hospital Aleksandrovska, 1 Georgy Sofilsky st., 1431 SOFIA
- Neuroscience and Behaviour Foundation, 15 Dimiter Nestorov st. 11th floor, Rm. 23, 1431 SOFIA

Croatia

- no address available yet

Cyprus

- no address available yet

Czech Republic

- * Fokus Usti nad Labem, Vojanova 601/48, 400 07 Usti n/Labem, E-mail: fokusul@volny.cz
- Czech Association of Mental Health, Zvonsrova 6, 13000 PRAHA 3, E-mail: cmhcd@cmhcd.cz

Denmark

- * [Landsforeningen Af nuværende og tidligere Psykiatribrugere](#) – LAP, Klingenberg 15, 2.t.h., 5000 ODENSE C. Tel: +45 (0)6619 4511, E-mail: lapp.dk@tdcads1.dk. LAP is the national association of users, ex-users and survivors of psychiatry in Denmark building on individual and collective membership and linking many different local and regional groups and organisations.
- * [Landsforeningen SIND](#): the Danish Federation for Mental Health advocates understanding and tolerance of people with mental problems and illnesses and their families. SIND seeks to attract more attention to mental health and make people care. SIND takes initiatives and support initiatives to promote mental well-being, prevention and treatment. The Danish association for mental health is a mixed organisation. Members are professionals, volunteers, relatives and (ex-)users of psychiatry. Address: SIND, Hostrups Have 50, 5 Sal, 1954 FREDERIKSBORG C. Phone +45-35-240 750, Fax +45-35-36 11 36, E-mail: landsforeningen@sind.dk
- * [Galebevægelsen](#), Dr. Abildgårds Alle 15, 1955 FREDERIKSBERG C. The Danish Madmovement is a network between small groups and individuals, most of them survivors of psychiatry.
- [Outsideren](#), Prinsesse Charlottesgade 28, 2200 KØBENHAVN N. The Outsider is a critical national magazine »looking at psychiatry from within«, written and produced by (ex-)users of psychiatry.

England

- * [MindLink](#), User-only organisation, is part of Mind which is British largest Mental Health Charity covering both England and Wales. MindLink is fully funded by Mind, to work with users and ex-users of mental health services in England and Wales so that they can contribute to, among other things, Mind's policies and campaigns. MindLink currently has around 830 users and ex-users in the network, some members live outside England and Wales all over the United Kingdom. MindLink has a structure of operation within Mind and there are terms of reference to enable MindLink to deliver its work. This structure includes having an Advisory Panel of 26 democratically elected members of MindLink who work with the whole membership as well as directly with Mind, Mind Local Associations and external mental health organisations including in Europe. There are two full-time

workers employed in MindLink and it is an essential requirement that they have direct, personal experience of mental distress. Address: MindLink, c/o Mind, 15 - 19 Broadway, London E15 4BQ, Tel. +44-(0)20-82152210, Fax: +44-(0)181-5221725, Email: m.chapman@mind.org.uk. MindLink Co-ordinator: Madie Chapman.

- * [UK Advocacy Network](#). UKAN is a national federation of independent mental health user run patients councils, support groups, advocacy projects and user forums. It collects and disseminates information about patients' councils, advocacy, projects and user forums and provides this information in order to facilitate wider development of user involvement and user led mental health services. UKAN has many groups in England, Wales, Scotland and Northern Ireland. Address: UKAN, 14 - 18 West Bar Green, SHEFFIELD S1 2DA, Tel: +44 (0)114-272-8171, Fax: +44-(0)114- 272 8171, E-mail: UKAN@can-online.org. Contact person: Liz Skelton liz@u-kan.co.uk
- * Brent Black African and Caribbean Mental Health Consortium, 3 Chesham Street, Neasden, London NW10 0BH
- * Loud & Clear, 22 - 24 High Road, Willesden, London NW 2
- * Survivors Speak Out, 34 Osnaurgh Street, LONDON NW 13 ND
- Service User Research Enterprise (SURE). SURE is the service user research unit at the Institute of Psychiatry, London. SURE involves service users in mental health research through training, capacity building, opportunities for participation in collaborative research projects and by conducting user led research. Address: SURE, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF
- Survivors Poetry, Diorama Arts Centre, 34 Osnaurgh St, London NW3 3ND, Tel. +44 (0) 207 916317
- [The uksurvivors list](#) was set up for all UK mental health survivors, disabled people and allies who are interested in networking together and discussing proposed new laws. It is a public list and anyone can join. To post a message, send it to: uksurvivors@eGroups.com
- [Survivors' United Network](#): electronic newsletter, organised by Andrew Hughes, Co-ordinator. E-mail: sun@artofawareness.co.uk
- [MadPride](#), E-mail: pete@shaughnessey.freeseve.co.uk
- * [Hearing Voices Network](#). Hearing Voices Network helps voice hearers to find their own ways of coming to terms with their experience. It co-ordinates of a network of self-help groups throughout the UK, produces a quarterly newsletter "Voices", sent to over 1.000 members, and produces information leaflets and other publications about voice hearing. HVN networks with many other groups and organisations across the country. Address: 91 Oldham Street, Manchester M4 1LW, Phone: +44-(0)161 834 5768, Email: hearingvoices@care4free.net. Volunteer co-ordinator/Administrator: Julie Downs , 91 Oldham St, Manchester M4 1LW
- [National Self Harm Network](#). We are a survivor-led organisation, founded in 1994. We are committed to campaigning for the rights and understanding of people who self-harm. PO Box 16190, London NW1 3WW. info@dividedwefall.fsnet.co.uk
- [Consumer Consultancy](#), 14a St Aubyns, Hove, East Sussex BN3 2TB. Phone Work: +44-(0)1273-748853. Fax: +44-(0)1273-724176. E-mail: insight@fastnet.co.uk. A consumer/survivor organisation based in Brighton. CC is involved in research, service monitoring, policy development and networking in the UK.
- [The Benzodiazepine Awareness Network International](#). E-mail: GCBURNS55@aol.com
- [Benzodiazepine.org](#): Prescription Drug Addiction – Information Site And Forum Color Benzodiazapine Addiction, Withdrawal And Recovery Information
- [The Heather Ashton Manual on How to Withdraw From Benzodiazepines](#): brand new 48 page manual containing information about the effects that benzodiazepines have on the brain and body and how these actions are exerted. Detailed suggestions on how to withdraw after long term use and individual tapering schedules for different benzodiazepines are provided. Withdrawal symptoms, acute and protracted, are described along with an explanation of why they may occur and how to cope with them. The overall message is that most long term users who wish to can withdraw successfully and become happier and healthier as a result.

Estonia

- * Hingerahu, Mai 34-71, PARNU EE3600
- * Patients Advocacy Estonia

- Eesti Pühhiaatriliste Patsientide, Esindusühing, Paldiski mnt. 52, TALLINN EE0006
- Meelerahu, Hiela tee 10, TALLINN EE0021

Faroe Islands

- Sinnisbati, MBF-húsið, Íslandsvegur 10 C, FO-100 Tórshavn, Faroe Islands. Phone: +298322544, E-mail: Sinnbati@post.olivant.fo

Finland

- * [Finnish Central Association for Mental Health/AFFINITY](#), Malmin kauppatie 26, 00700 HELSINKI, Phone +358-(0)9-351600, mobile +358-(0)50-5979441, Fax +358-(0)9-3514364, E-mail: inkeri.aalto@mtkl.inet.fi
- * Advocacy France. Registered and democratic organization from (ex-)users and survivors of psychiatry, professionals and relatives. About 300 members all over France, representative organization, recognized by government, active at congresses at other public assemblies. Address: Advocacy France, 8, rue Thureau d'Angin, 75015 PARIS. Tel. : +33-1-45.32.22.35, Fax : +33-1-45.32.22.35, E-mail: Advocacy.France@noos.fr
- * "[l'Autre Regard](#)", association of users in RENNES, France (FNAP Psy's member), 2 square de la Rance, 35000 RENNES. Phone: +33 (0)2- 23302466, +33-(0)2-99316343; Fax: +33 (0)2-99311868. E-mail: autre.regard1@libertysurf.fr. Face to psychic pain an original association of leisure (since 1985, 200 members).
- Groupe Information Asiles, BP 172, 75622 PARIS CEDEX 13
- [International Association of Spiritual Psychiatry](#): A non-profit organization, created in 1994, based in France, dedicated to promote spiritual approaches to mental health and psychiatry, through conferences, newspapers and books.
- Daily [Net-Journal on wisdom, health and spirituality](#) in the French language

Georgia

- no address available yet

Germany

- * [Bundesverband Psychiatrie-Erfahrener e.V.](#) – BPE, Thomas-Mann-Str. 49a, 53111 Bonn: The German organisation of (ex-)users and survivors of psychiatry with links to the [regional BPE-organisations](#) and to [other German organisations, groups and institutions](#)
- * [Forum Anti-Psychiatrischer Initiativen e.V.](#): Organisation consisting of antipsychiatric individuals members in the German-speaking countries, c/o Peter Lehmann, Zabel-Krüger-Damm 183, D-13469 Berlin
- * [Verein zum Schutz vor psychiatrischer Gewalt e.V.](#): Organisation running the Berlin Runaway-house (presentation in the German, Norwegian and English language): [Weglaufhaus Berlin](#)
- [Netzwerk Stimmenhören](#) e.V. (Hearing Voices Network), c/o Pinel, Ebersstr. 67, D-10827 Berlin, Tel. +49 – (0)30 – 78718068 (Tuesday 16 – 19 Uhr), E-mail: stimmenhoeren@gmx.de
- Netzwerk Brandenburg e.V.: Working group in the Bundesland Brandenburg – survivors of crises (and psychiatric survivors) speak out for themselves and with each other – a place to contact other survivors and get information – salutogenic approach, empowerment methods. [Netzwerk Brandenburg e.V. – Landesarbeitsgruppe. Krisen-(und Psychiatrie-)Erfahrene sprechen für sich und miteinander – Kontakt- und Informationsstelle – salutogeneseorientiert, Empowerment-Arbeitsweise.] Address: Netzwerk Brandenburg e.V., Libellenweg 4, D-14772 Brandenburg, Phone +49-(0)3381–795920, Fax +49-(0)3381–795921, E-mail: Netzwerk-Brandenburg@web.de

Greece

- * [PEPSAEE](#) (Panhellenic Union for the Psychosocial Rehabilitation and Work Integration). This NGO and non-profit union operates since 1997 within the Greek reality of the Mental Health sector and the framework of the Psychiatric Reform and is officially recognised by the Greek government. Address: PEPSAEE, Harissis 6 (off M. Voda), 104 39 Athens. Phone/Fax: +30 10 8818946 , E-mail: pepsaee@otenet.gr
- * KLIMAX, N. Nikodimoy 23 Plaka, ATHENS

Hungary

- * [Voice of Soul Association](#): The biggest (ex-)user/survivor of psychiatry organisation in Hungary. Address: Klauzál u. 31.f.6, H-1072 BUDAPEST
- * Magic Hill, c/o Soteria Foundation, Szemere u. 19 V. 5., 1054 BUDAPEST
- Ray of Light, Várkörút 6, SKÉKESFEHÉRVÁR, 8000

Iceland

- * Gedhjálp, Tungata 7, 101 REYKJAVIK. Phone +354-5-701 700, Fax: +354-5- 701 701, E-mail: gedhjalp@isholf.is

Ireland

- * [impero](#): the Irish Mental Patients' Educational and Representative Organisation, c/o Sean Crudden, Jenkinstown, Dundalk, Co Louth, Telephone and Fax +353 42 93 71310, E-mail: impero@iol.ie. [More information](#)
- * Mind Yourself! (and 'Foyle Advocates'), 15 Magazine Street, Derry BT 48 6H H. Phone: 01504 263461
- Mental Consumer Association, Philipsburgh Avenue, Fairview, DUBLIN 3
- Foyle Advocates, Derry, phone: 01504 263461
- WIP, St. Brigid's Avenue, Portumna, CO. GALWAY
- Newry and Mourne MH Forum, Newry, 01693 252423
- Holywell Patients Council, Ward 9 Corridor, Holywell Hospital, 60 Steeple Rd, Antrim, BT41 2RJ

Italy

- * [AISMe](#) (Associazione Italiana per la Salute Mentale). Activities: Mental Health promotion initiatives (Mental Health Day, Mental Health Week); promotion and support of self-help groups for users and relatives; building relationships with services, local governments and other organisations. Address: Via Forlanini 64, 50100 Firenze. Tel. + 390 338 2998938, Fax + 390 55 413049, E-mail address: pipini@dada.it. Contact persons: Miccinesi Donatella, Pino Pini. [Short information in the English language](#) / [Informazione in Italiana](#)
- Associazione per la lotta Contro le, Malattie Mentali, Via Vanchiglia 3, 10100 TORINO
- * Gruppo Auto-Aiuto di Cafaggio, c/o AISME, Via Livi 7, 50047 PRATO (FI)
- * Gruppo Auto-Aiuto Massa Carrara, Piazza Cesara Battista No. 1, 54033 CARRARA
- * Gruppo di Auto-Aiuto Merano, Raffeingasse 1, 39011 LANA (BZ)
- Cooperativa La Luna Nel Pozzo, Via Appennini 165, 20151 MILANO

Kazakhstan

- no address available yet

Kyrgyzstan

- no address available yet

Latvia

- no address available yet

Lithuania

- * »Biciuliai«, Muitines 2, KAUNAS. The main goal of the club – rehabilitation of psychically disabled patients. The

main principle of club's activities – mutual assistance of the club-members.

- * Club 13 and Co, Vilnius Psychiatric Clinic, Parko 15, VILNIUS 2001

Luxembourg

- * [Psychiatrie Selbsthelf](#), 16, Rue Alfred de Musset, 2175 LUXEMBOURG. Phone +352-333347, Fax +352-333786, e-mail: atw@atp.lu
- Ateliers Therapeutiques Walferdange, 89, Rue de l'Eglise, 7201 WALFERDANGE. Phone +352-333347, Fax +352-333786, e-mail: atw@atp.lu

Macedonia

- no address available yet

Malta

- no address available yet

Moldova

- no address available yet

Monaco

- no address available yet

Netherlands

- * [Clientenbond](#). The Clientenbond is an association with personal members and group members. They are knowledgeable by the government and the providers of health care as a partner to negotiate with. The structure is the general assembly, the board and then the voluntary workers and the staff. We have about 1700 individual members and 60 groups like patient councils. Address: Clientenbond, Postbus 645, NL-3500 AP UTRECHT, Tel. 0031-(0)30-2521822, E-mail post.clientenbond@planet.nl
- * [LPR](#). The patients council movement within the mental health care in the Netherlands. LPR, Postbus 3305, Churchillaan 11, NL-3502 GH UTRECHT, Phone +30-(0)29-33233, Fax: +30-(0)29-30244, E-mail: info@lpr.nl. [More English information](#)
- [Deviant](#) is a Dutch magazine for innovation and democratization of mental health services and connected fields. Deviant is a forum for all people involved: helpers, clients/users, family members, scientists, policy makers, politicians, journalists, financiers and other people interested.
- [Werkgroep Stap](#): Stap is a small group of people supporting Russian mental health clients in a material way. Address: Stap, Pimpemel 3, NL-1902 JJ Castricum. Phone: +31-(0)251-655800, E-mail: H.vanderleest@tiscali.nl

Northern Ireland

- Erne Advocacy c/p Clare House, 51 Chanterhill Rd, Enniskillen, Co Fermanagh Cause Users Group, phone: 01960 367728
- Association Network, Belfast, phone: 01232 328474
- Holywell Patients Council, Ward 9 Corridor, Holywell Hospital, 60 Steeple Rd., Antrim, BT41 2RJ
- Mark Doran UKAN N.Ireland Representative, phone: 01693 68846 / Martha McClelland, UKAN N.Ireland Representative, phone: 01504 263 461. E-mail: mindyourself@derry15.freeserve.co.uk

Norway

- * [AURORA](#), Postboks 8815 Youngstorget, N-0028 OSLO, E-mail: aurora@aurora-stotteforening.no. »AURORA is a support association for people with mental health problems.«

- * [Galebevegelsen i Oslo](#) – the Mad People's Movement in Oslo, c/o Elin Sverdrup-Thygeson, Østgaardsgate 23 B, N-0474 OSLO
- * [Mental Helse Norge](#), Postboks 298, N-3701 SKIEN. Phone: +47-35-534 370, Fax: +47-35-530 930, E-mail: post@mentalhelse.no
- * [We Shall Overcome](#) – Norway's oldest national organisation of (ex-)users and survivors of psychiatry. Address: WSO, postboks 8817 Youngstorget, N-0028 Oslo, E-mail: wso-org@frisurf.no. To view Søkelyset you need the Acrobat Reader from Adobe: www.adobe.com/products/acrobat/readstep2.html
- FAMPO (Folkeaksjonen Mot Psykiaternes Overgrep/Popular Action Against Psychiatrists' Assault), c/o Chairman Dag Hiåsen, N-3355 Solumsmoen
- [»Norwegian Antipsychiatry«](#). E-mail: jo@lund.as
- atelierlivskraft.no/englishintro.htm This site contents artwork made of users of psychiatry and other amateur-artist with no connection to healthservices. There are two discussion fora there. One for psychiatric experiences, and one for people interested in arts and society. There are also two similar chatrooms there. The search words: psychiatry, critical psychiatry, art, psychology, chat, public chat, mailfora, English, French, German
- [eGroups kritiskpsykiatri](#): Norwegian website to promote users of psychiatry with artistic skills. It contains discussionfora and critical socialpolitical articles, and critical articles about psychiatry

Poland

- * [Braterstwo Serc](#), ul. Jozefa 1, 31 - 056 KRAKOW, E-mail: biuro@braterstwo.org.pl
- * Amicus, ul. Grottgera 25 A, 00-785 WARSAWA
- Nadzieja, Oddz. Psychiatryczny, ul. Wysokie Brzegi 4, 32-600 OŚWIĘCIM
- Psyche, ul. Sobieskiego 67 Ip., 43300 BIELSKO – BIALA

Portugal

- * (ex-)Utentes da Psiquiatria de Portugal, Unidade de Reabilitação, Hospital Miguel Bombarda, Rue dr. Almeida Amaral, 1150 LISBOA
- * Pro Associacao Doentes
- * Esti(g)ma, Jose Garcia, Rua de Buenos Aires No.12, port, 1200 LISBOA
- ARIA, Rua Joao de Barros, 12, 1300 LISBOA. Phone: +351- 2 13641099, Fax: +351 - 2 13660165
- ASSOCIACAO DE APOIO E SEGURANCA PSICO-SOCIAL, Rua 4 No 10, Bairro do Alto da Ajuda, 1300 LISBOA

Romania

- * Orizonturi, Str. Irandafilor nr 2, Cimpulung, MODOVENESC 5950, jud. Suceava
- Armonia, Str. Juliu Maniu nr. 38, 1900 TIMISOARA
- Romanian League for Mental Health, Sos. Mihai Bravu 90-96, bl D 17 sc 4 apt 49, Sectorul 2, BUCHAREST
- Estuar Foundation, Sos Oltenitei nr. 188, bl 1, sc. B etj. 4, apt 54, Sectorul 4, BUCHAREST
- Romania-American Mental Health Alliance, Dr 1 Cantacuzino str. nr.14, 2200 BRASOV
- * (ex-)Utentes da Psiquiatria de Portugal, Unidade de Reabilitação, Hospital Miguel Bombarda, Rue dr. Almeida Amaral, 1150 LISBOA
- * Esti(g)ma, Jose Garcia, Rua de Buenos Aires No.12, port, 1200 LISBOA

Russian Federation

- no address available yet

San Marino

- no address available yet

Scotland

- * [New Horizons Borders](#). Address: 3, Market Street, GALASHIELS, TD1 3AD. Tel. (0)1896 755510. "We are a user managed organisation." E-mail: admin@newhorizonsborders.freemove.co.uk
- Scottish Users Network, c/o EAMH, 40, Shandwick Place, EDINBURGH

Slovakia

- * ~~Slovakian Association Premeny. Premeny is the national federation of the nine regional organizations of users and ex-users of psychiatry and exists to support the establishment and development of new and existing user organizations in Slovakia. In May 2002 Premeny has 9 members. Phone: +421 56 6883281, E-mail: premeny@stonline.sk~~
- Pozdrav, areál Psych. nemocnice Stránany, 071 01 MICHALOVCE . Member of Premeny.
- * RADOST, Mgr. Drahoslava Kleinová, Rastislavova 12, 04001 KOSICE . Member of the families-organisation Opora
- Viktoria, Sklenárova 40, 821 09 BRATISLAVA. Member of Premeny.

Slovenia

- * ALTRA, Grabloviceva 27, 1000 LJUBLJANA
- * [Paradoks](#), Vrhovci, c, XVII. št.40, 1000 LJUBLJANA. Paradoks is in Slovenia the only mental health organisation which is established and run only by users and exusers of psychiatry. Phone: +386 1 422 85 61, Fax: +386 1 422 85 63, e-mail: paradoks1@siol.net
- * OZARA, Meljska 12, 2000 MARIBOR
- * VEZI, Storje 26, 6210 SEZANA. Phone/Fax: +386 5 768 52 00, E-mail: drustvo.vezi@siol.net
- SENT, Vilharjeva 22, 1000 LJUBLJANA. Phone: +386 - 1 431 94 08, Fax: + 386 - 1 131 94 18, E-mail: sent@siol.net

Spain

- * FEAFES internacional, O'Donnell, 18-2 G, 28009 MADRID. Phone: +34-(0)91-915759226, Fax: +34-(0)91-5767310, E-mail: feafes@mad.servicom.es

Uzbekistan

- no address available yet

Wales

- * [The All-Wales User and](#) * Vita, 8 Vorovsky, str. apt 34, KIEV 254 053
- [Survivor Network](#), US Network, Suite 3, 1 North Parade, Aberystwyth, Ceredigion, SY23 2JH. Telephone: +44-(0)1970-626-230

Yugoslavia

- * Individual member: Jasna Russo, Novalisstr. 13, D-10115 Berlin (Germany), Phone +49-(0)30-2859045, E-mail: jasnarusso@yahoo.com

ENUSP

"Should pharmaceutical companies supply the public with information on prescription medicines? *The views of EU-based patient groups*"

Dear Sir/Madam,

I would like to invite you to participate in an important survey of patient opinions, now being conducted among key patient groups within the EU.

The survey asks whether pharmaceutical companies should supply the public with significantly more information about prescription drugs than they do at present. The survey results will be published, in report form, in May 2002 by IAPO and by PatientView, who are a UK-based independent healthcare market-research organisation.

We strongly urge you to participate in the survey, as it will provide your group and your members with an unprecedented opportunity to express an opinion on this vital subject. The need for the survey is urgent. The EC has announced the launch of a number of pilot schemes regarding greater supply of information by pharmaceutical companies. It is vital that patient groups get a chance to express their point of view. The results of the survey could prove a powerful tool in discussions with the European Health Policy Forum (next due to meet in June 2002). By participating, you will be part of an exercise that could affect the direction of EC legislation.

The survey is designed to be all-inclusive

The survey has been designed to include a representative sample of authoritative patient groups based in the EU. Thus patient groups in all EU countries, covering virtually every disease area, and ranging in size from small to large, have been included in the sample. Because most patient groups have yet to formulate a policy statement on whether pharmaceutical companies should provide more information about prescription medicines to the public, IAPO has decided that all results should be published anonymously. The survey's report will merely cover patient groups' views in aggregate.

How we would like you to be involved in the survey

Attached to this letter are two introductory pages briefly explaining the EC and the US approaches to the subject. Also enclosed is a copy of the questionnaire. A senior official within your organisation should answer the questionnaire. Ideally, the opinions expressed should represent the views of the majority in your patient group. However, if a consensus view cannot be provided, the personal opinions of the senior official will be acceptable.

There are two ways you can respond:

1. You may, if you wish, fill in the questionnaire yourself. The questionnaire is laid out in a simple multiple-choice fashion. Completing it should only take about 15, or at most, 20 minutes of your time. The completed questionnaire should then be sent to the survey managers, Patient View, in the stamped addressed envelope supplied. IAPO would be grateful if you could return your completed questionnaire within about two weeks, so that the report's publication deadline of May can be met.
2. Alternatively, you may dictate your answers over the telephone to a Patient View researcher. If you wish to respond this way, you should wait for a Patient View researcher to telephone you. Researchers will be telephoning about two weeks after questionnaires have been sent out.

As mentioned earlier, every patient group's contribution will be included among the survey findings on a strictly anonymous basis. Some patient groups, however, may choose to be listed in the report's appendix as contributors to the survey (of course, their actual responses will still remain completely anonymous). Inclusion in the appendix is entirely optional.

Thanking you in advance for your cooperation. As a contributor your group will be entitled to a complimentary copy of the resulting report, which will be sent to you on publication IAPO hopes that the significance of the project will ensure a good response to this survey.

Yours faithfully,

PATLENTVIEW, on behalf of
International Alliance of Patient Organisations

Explanatory note for patient groups

1. EC proposals regarding pharmaceutical companies supplying the public with information about prescription drugs¹

In 2001, the EC proposed that patients should be given better access to information on prescription drugs. As part of this process, industry should be permitted to supply "good, reliable information" about prescription products in an appropriate and well-controlled way.

The EC emphasises that the proposal is concerned with the supply of information NOT with advertising

Some facts

- Pharmaceutical companies are currently legally prohibited from talking about their products directly to EU-based consumers.
- Prescription product information is already available to patients in Europe through the Internet on websites hosted in America.
- In 2002/3, the EC is set to begin a five-year pilot study in three chronic disease areas: diabetes, HIV/AIDS and asthma. Patients and patient groups will be able to request information about drugs prescribed for any of the three disease areas.
- The nature, content and policing of the pilot studies has yet to be decided.

Extracts from the EC website. Address is:

<http://europa.eu.int/commissioners/liikanen/media/slides/pharmaceuticals/tsld006.htm>

2. Direct-to-consumer (DTC) prescription-drug advertising in the United States²

The situation regarding the provision of information about prescription drugs to the public is very different in the US. Pharmaceutical companies are permitted to provide the public with information about prescription drugs. They can also advertise prescription drugs. The US Food and Drug Administration (FDA-the agency responsible for approving all prescription drugs in the US) regulates DTC prescription-drug advertising. The FDA has defined DTC prescription-drug advertising as follows:

"The FDA generally interprets the term "advertisement" to cover information other than labelling that promotes a product. The term includes promotions broadcast on television and radio, conducted by telephone, or printed in magazine and newspapers."

A brief history

- In the US, no laws or regulations have ever prohibited the advertising of prescription drugs directly to consumers.
- In 1962, the US Federal Food, Drug and Cosmetic Act and related regulations imposed controls on DTC prescription-drug advertising. The Act stipulated that if a drug manufacturer advertised a brand product and its uses, the advertisement had to mention the drug's side-effects. The FDA acted as national regulatory body.
- To avoid mentioning side-effects in their advertisements, drug manufacturers then promoted only the name of a branded drug and/or encouraged patients to visit their local doctor. These advertisements did not have to carry warnings of side-effects, and therefore failed to provide the public with vital information
- To promote better dissemination of medical information, the FDA issued draft guidance in 1997. The guidance permitted drug manufacturers to advertise brand products directly to consumers on TV and radio, and to mention a product's use. Advertisers were told that they need give only a brief resume of side-effects--so long as the advertisement was not false or misleading. In particular, advertisements had to present a "fair balance" between benefits information and risks information.

- Since 1997, the volume of DTC prescription-drug advertising in the US has ballooned. A number of complaints have been made about misleading prescription-drug advertisements. Complaints tend to focus on several factors: advertisements do not provide a complete picture of the advertised drugs; advertisements damage the patient-physician relationship; and advertisements increase patient demand for (and therefore costs of) the advertised drugs. But equally, other prescription-drug advertisements have been hailed as important educational tools in an era when patients want to be more involved in their own healthcare.

² Extracts from the US Food and Drug Administration website. Addresses are:

http://www.fda.gov/fdac/features/1998/198_ads.html

<http://www.fda.gov/cder/ddmac/presentations/ostrdtc3O1/sld001.htm>

Important

ENUSP does not accept any money from the drug industry. National, regional and local organisations, however, take their own decisions. For reasons of transparency, we refer to a (co-)financing by pharmaceutical companies as far as we know about it by the addition "sponsored by pharmaceutical companies".

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Treatment-induced suicide. Suicidality as a potential effect of psychiatric drugs.

Peter Lehmann

(Worked-over) Contribution to the conference *Coping with stress and depression related problems in Europe*, organized by the World Health Organization, the European Commission and the Federal Ministry of Social Affairs, Public Health and the Environment (Belgium), Brussels, October 25 – 27, 2001.

Depression can have many causes: psychosocial and political conditions, neurological diseases, metabolic disorders, aging, toxic substances and drugs. Physicians generally focus on organic or supposed organic depressions, for which they prescribe psychiatric drugs and electroshocks. It is hard for them to accept that many psychiatric drugs can cause or increase depression and suicidality. But in medical and pharmacological specialist literature there are many reports about the depressive effects of psychiatric drugs. In particular, neuroleptics, the so-called antipsychotic drugs like haloperidol (one brand name for which is Haldol) and clozapine (one brand name for which is Leponex) often initiate depression and suicide. A suicide register with special regard to associated psychiatric drugs, electroshocks, restraint, and other forms of psychiatric compulsion could be effective as a form of prevention and lower the occurrence of depression and suicides.

Drug-associated depression and suicidality.

Neuroleptics have a blocking effect primarily against the transmitter dopamine resulting in Parkinson's disease. This is a complex of symptoms, characterized by walking with a stoop, muscle tremor and blurred speech. Parkinson's disease regularly results from dopamine blockage. The potency of neuroleptics is defined by their power to create Parkinson's disease; this is not an unwanted side effect, but therapeutic main effect as defined by psychiatrists.

Parkinson's disease, primarily a disease of the movement apparatus, involves alterations on the psychic level, too. Neurologists define them as Parkinson personality. It is a complex of symptoms including apathy, loss of willpower, depression and suicidality, and states of confusion and delirium (Fünfgeld 1967, p. 13ff). In 1955, after the first administrations of the neuroleptic prototype chlorpromazine (Largactil, Megaphen and Thorazine), German psychiatrist Hoimar von Ditfurth pointed to the parallels between the emotional Parkinsonian deadening after a brain disease and the emotional deadening after neuroleptic treatment:

As we may believe, it looks as if the psychic alterations provoked by Megaphen especially on the emotional level are of the same nature as the "affective deadening and restriction", which is registered so often at postencephalitic parkinsonists (people with Parkinson's disease after subsiding of an acute brain inflammation, P.L.). (p. 56)

Thus, depression and suicidality are normal effects of neuroleptics, and psychiatrists accept them without question.

Frank J. Ayd (1975) from the Psychiatric Department of the Franklin Square Hospital in Baltimore, USA, wrote:

There is now general agreement that mild to severe depressions that may lead to suicide may happen during

treatment with any depot neuroleptic, just as they may occur during treatment with any oral neuroleptic. These depressive mood changes may transpire at any time during depot neuroleptic therapy. Some clinicians have noted depressions shortly after the initiation of treatment; others have observed this months or years after treatment was started. (p. 497)

Otto Benkert and Hanns Hippus (1980), two German psychiatrists, answered the question whether suicidality prehaps could be caused by an excessive dosage:

Depression, suicidality, states of excitement and delirium under the influence of drugs generally occur during doses prescribed by the treating physician. (p. 258)

Empirical data about suicides caused by psychiatric drugs are hard to find for many reasons, as psychiatrists themselves write. Psychiatrists do not regard or blame their courses of treatment as the cause of depression (Lehmann 1996, p. 111). Asmus Finzen of the Psychiatric Department of the University Berne, Switzerland, showed that the likely number of suicides in psychiatric institutions is vast, too. Correct figures are, however, hard to find because

... In illness documents and discharge summaries you could often find no notice about the patients' suicide or death. If the suicide happened during a vacation, the patient's discharge date might be backdated. If the suicide attempt did not lead to an immediate death, in illness document and statistics he would be considered as moved to the internal or surgical clinic. (1988, p. 45)

R. de Alarcon and M.W.P. Carney, two English psychiatrists, studied depressive mood changes after administration of neuroleptics with other variables staying the same. In the *British Medical Journal* they reported on suicides under the influence of fluphenazine (market name for instance Moditen), administered as part of community treatment, and described a fluphenazine trial on a 39-year-old man who had already tried to kill himself under the influence of this drug. When the psychiatrists had realized that this man had regularly developed suicidal intentions some days after the biweekly depot injections, they wanted to witness the mood-worsening effect of the neuroleptic with their own eyes. In the psychiatric institution the man was observed over a period of four weeks, without being treated with neuroleptics, and without displaying anything remarkable in his mood. Then they injected him 25 mg of fluphenazine intramuscularly:

During his stay in hospital he was interviewed by one of us (R. de A.) three times a week. For a week before the injection, during the day he was not due for an interview. His condition was discussed with the chief ward nurse and the nursing reports were perused. He was given the trial injection on a Wednesday at 3 p.m.; by mid-afternoon on the following day he felt low, wanted to be left on his own, and had no desire to talk to anyone, read, or watch television. He took to his bed at about 4 p.m. In the opinion of the charge nurse he was a suicidal risk. During the interview on Friday the change in external appearance was striking – he looked gloomy, he did not respond with a smile to a joke, and there was no spontaneous conversation. His answers were limited to what was strictly necessary. He denied any paranoid or hypochondriac ideas or any feelings of guilt. He simply said that he felt very low and if he were alone in digs, he would take his life. By Friday evening there was some improvement, and when he was interviewed again on Saturday he had returned to his usual normal self. (... de Alarcon and Carney gave a resume of their findings, P.L.) that some patients may become severely depressed for a short period after an injection of fluphenazine enanthate or decanoate. So far no pattern has been established regarding when and in whom this is likely to occur. The lack of adverse effects in the past is no indication that these may not appear in the future. In the trial case, for instance, the patient received fluphenazine enanthate for more than six months before he began to react repeatedly to the injection with severe depression, and the same thing happened with other cases in the series. (1969, p. 565f.)

In his placebo-controlled study, psychiatrist Peter Mueller from the Psychiatric Department of the University of Göttingen, Germany, found that a much higher percentage of people treated with psychiatric drugs had depressive symptoms than people treated with placebos. In relation to lessening or withdrawal of the psychiatric drugs he wrote:

The depressive mood lifted in 41 cases out of 47, in only two cases there was no change, and in four cases the effect was dubious. It was very surprising to see that in the predominant number of cases the reduction of the doses (normally to half of the former dose) alone led to an improvement in the depressive symptoms. Often it was only a partial improvement, but even this brought clear relief to the patient. On the other hand, in other patients, or in the same ones whose situation improved only slightly after taking lower doses, complete withdrawal made them feel much better. Some patients reported that only now did they feel completely healthy again, as they had long before their depression. The depressive symptoms, which were seen to be unchangeable by some psychiatrists, and which could have possibly been perceived as a start of organic disorder, vanished completely. The possible argument that these could be psycho-reactive effects caused by the patients' relief about the withdrawal of the psychiatric drug is refutable, because nearly all patients received depot injections and were not informed about their doses or got placebo injections. (...) Their change was quite impressive to themselves, their relatives and their medical examiners in some cases. The patients reported that now they felt completely healthy again. In the group of people still treated with psychiatric drugs, this was

mostly not the case. These results quite definitely speak for pharmacogenetic influences and against psychiatric morbidity developments.

Mueller resumed:

Depressive syndromes after the remission of the psychoses and under treatment with psychiatric drugs are not rare, but occur in about two thirds of patients, and sometimes even more frequently, especially when depot drugs are given. Without treatment with psychiatric drugs, depressive syndromes after a complete remission are only found in exceptional cases. (p. 72)

Mueller's reports are supported by many of his colleagues (Lehmann 1996, p. 57 – 87, 109 – 115). Some examples are Raymond Bategay and Annemarie Gehring (1968) of the Psychiatric Department of the University of Basel, Switzerland, who warned, after a comparison of treatment courses before and after the era of psychiatric drugs:

During the last years, a shifting of the schizophrenic syndromes to a depressive syndrome was repeatedly described. More and more schizophrenias show a depressive-apatetic course. It became clear that what develops under psychiatric drugs, is exactly something that should be avoided with their help and that is called a defect. (p. 107ff)

Walther Pöldinger and S. Siebern of the Psychiatric Institution Wil, Switzerland, wrote:

It is not unusual that depressions caused by medication are marked by a frequent occurrence of suicidal ideation. (1983, p. 131)

In 1976 Hans-Joachim Haase of the Psychiatric Institution Landeck, Germany, reported that the number of perilous depressive occurrences after a treatment with psychiatric drugs increased at least ten times when compared to those before the introduction of psychiatric drugs. The increase in the suicide rate is "alarming and worrying", said Bärbel Armbruster of the Psychiatric Department of the University of Bonn, Germany, in the *Nervenarzt* in 1986 – without, nevertheless, alarming (ex-) users and survivors of psychiatry and their relatives, or even the public.

Rolf Hessö from the Psychiatric Department of the University of Oslo, Norway, informed about the development in Finland, Sweden and Norway in 1977; it seemed to be clear

...that the increased incidence of suicide, both absolutely and relatively, started in the year 1955. This was the year that neuroleptics were introduced in Scandinavian psychiatric hospitals. (p. 122)

In 1982 Jiri Modestin wrote about his place of employment, the Psychiatric Department of the University of Berne, as well as the neighbouring psychiatric institution Münsingen:

Our results show a dramatic increase in the suicide frequency among the patients in Berne and Muensingen in the last years. (p. 258)

First-hand reports about depression and suicidality.

In the book "To come off psychiatric drugs", published originally in 1998, Regina Bellion from Bremen (Germany) gave a report about her psychic condition under the treatment in the community:

Alone at home. Three times a day I count my Haldol drops. I don't do much else. I sit on my chair and stare in the direction of the window. I have no sense of what is happening outside. I find it difficult to move. Nonetheless I am able to get up everyday. I don't notice that the apartment is getting dirty. It doesn't occur to me that I should cook something. I don't wash myself. I don't even ask myself if I stink. My misery progresses – but I don't even notice. I vegetate behind my neuroleptic wall and I am locked out of the world and out of life. The real world is further from me than Pluto is from the Sun. My own secret world is also gone – my last refuge, and I had destroyed it with Haldol. This is not my life. This is not me. I may as well be dead. An idea has begun to take shape. Before winter comes I will hang myself. But before that I want to try and see if my life would be different without Haldol. I reduce the number of drops. I take fewer and fewer until I arrive at zero. After one month I am clean. Then I begin to notice how unkempt I am. I wash my hair, make the bed, clean the apartment. I prepare a warm meal. I even enjoy doing this. I can think again. (Bellion 2002)

Another user of psychiatric drugs, living in Bremen too, had gotten a prescription of Haldol and the antidepressant Aponal (doxepine); under the influence of this combination she tried – fortunately without success – to end her suffering by suicide:

When I got out again I would sit in my kitchen in front of the water faucet, thirsty but yet unable to pour myself a glass of water or to bite into the bread that had become stale and hard. The supermarket was not far away, but I couldn't manage to get up and so I wished that I were simply dead so that I would have some peace at last. I was broken by my

illness. I saw it as a punishment for two dark points in my life. Worst of all was the vicious circle of endlessly recurring psychotic patterns of thought. I tried again and again to think of something else even just for a moment – but it didn't work. My thoughts always revolved in the same circles, a hundred times a day, sometimes at a time-loop tempo in slow motion, other times constantly accelerating until my brain was spinning. And that was hell for me, the devil's game. I felt damned and abandoned by God with no hope of salvation. I could do nothing but suffer through this film, my life, lying down. I knew that I had to learn to have faith again, but I couldn't, and so I tried to end my life. (Marmotte 2002)

Atypical psychiatric drugs have suicidal effects, too, as the report of Austrian Ursula Fröhlich in *Brave New Psychiatry* shows:

to be continued

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translated by Pia Kempker

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**FORTHCOMING EVENTS :
THE SPRING 2002 AND OUR BOARD MEETING IN THE NETHERLANDS
APRIL, AMSTERDAM-UTRECHT : t o p i c s : -**

- **M O N E Y**
- **M E M B E R S H I P** (clarification of membership list)
- **C O O P E R A T I O N**
- **P U B L I C I T Y** (issues with the newsletter)
- **S T R U C T U R E** (desk in Berlin)
- **A N T I - S T I G M A C A M P A I G N S**

ENUSP

WELCOME HOME! It seems to be more than probable we have a new member from Bosnia Hercegowina/Serbian Republic. The same means we have a new stable partner country- see: organigramme, next page.

The opening meeting held by courtesy of the Hamlet Trust London last fall in Budapest by appointment of our Chair, Gabor Gombos allowed him to think the Federation /see the list/ to be recommended as a fully rights member of ENUSP. It is obvious the Board will approve it in a few weeks. NEXT ARE the two Czech organisations, one from Liberec and the second called HOPDN from Pelhrimovo.

LOOK AT the organigramme, page 14 prepared by Pia Kempker.

The work shows only these countries we keep our links stable and certain and only from "geographical" Europe. After the most recent Board meeting we shall add all revised and checked up data upon the others mainly those who were placed in the former Soviet Union in the past, like Turkiestan, Uzbekistan, Georgia and so on.

Note: B i H SR = Bosnia and Hercegowina + Srb. Republica, a new state in the map of Europe, now the ENUSP country.

Page 14 (size: 56 KB):

please open: www.enusp.org/newsletter/2002-3-p-14.pdf