



# On the Road to Activism



**The Eurasian Harm Reduction Network (EHRN)** - formerly the Central and Eastern European Harm Reduction Network - is a regional network with a mission to support, develop, and advocate for harm reduction approaches in the field of drugs, HIV/AIDS, public health, and social exclusion by following the principles of humanism, tolerance, partnership, and respect for human rights and freedoms. At the moment over 300 organizations and individuals from 27 countries of the Central and Eastern Europe and Central Asia are members of Eurasian Harm Reduction Network.

See [www.harm-reduction.org](http://www.harm-reduction.org) for details.

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# Introduction

*“My generation can feel the pain,  
but goes under the whip again.”*

**Konstantin Kinchev**

All the authors of this book have been working in harm reduction for the past ten years and have observed various developments on the drug scene, but as long as ignorance and fear of the unknown persist, we all will have work to do.

In order to understand how deeply rooted prejudice is in society, we can look at statements like “marijuana is a springboard to heroin, and heroin users are incurable and live a maximum of five years” – which are often pronounced publicly by politicians, reported in the media, and expressed by medical doctors, sociologists, teachers, and others.

These statements sound ridiculous to those who are knowledgeable on the subject. It is clear that marijuana is in no way a springboard to hard drugs, and users may, if they wish, get treatment and live to a ripe old age. We know about it not from hearsay, but from our first-hand experience of working in this sphere for more than a decade. Just as there are no universal methods of addiction treatment, there are no universal ways of addressing social problems related to drug use. Instead, it requires long-term and painstaking efforts directed at every single person.

But people in the street believe the myths created by government bureaucrats and publicized by mass media, and once they see a “drug addict” they hide their wallets and try to avoid him as much as possible. Potential employers believe the myths and say “no” without hesitation. Medical doctors believe the myths and deny drug users every type of medical treatment and care. Police are firmly convinced that the myths are true, and send all drug

users to prison without regard to individual circumstances. Who else? Journalists, politicians, next-door neighbors, friends, family...

Just one phrase... experience reveals that one phrase is enough to start a witch hunt. And there is also AIDS, hepatitis, tuberculosis... They scare people even more, and the public then demand to "toughen," "protect," "strengthen," "isolate," "destroy," "shoot them all down," "quash them."

Of course, one gets used to things. One may just give up and hope that worse may not come to worst. But unfortunately, things do not work this way, and the life of every drug user proves it. The problems are numerous, and new problems keep cropping up: how to access effective treatment for drug addiction, HIV, hepatitis, and so on; how to get a job; how to avoid prison and where to find a good lawyer. The list goes on.

What can be done in this situation? There is only one way, and it is not optional: try and change the situation ourselves. It is called activism. Water wears away stone, as they say. There are many examples - *some of them are described in this book* - where drug users' activism helped to drive their problems away. Sometimes drug users realized that they are they are in a position to understand, assess and effectively solve their own problems.

The HIV epidemic inspired many drug users to take action because so many people did not care whether or not drug users would survive. This forced them to come together in search of a solution, and it worked. First in Western Europe, and then progressively further to the east, drug users began to form groups to address some of the key problems affecting them and to advocate for their interests. It was the beginning of activism and community organizing.

It often started with a self-help group set up to solve some immediate problem - what doctor to see, where to buy cheaper medications, how to spend leisure time, etc. A graphic example was the fight waged by the Dutch drug users back in 1970s for the right to buy prescription syringes to avoid contracting hepatitis. It was the beginning of the harm reduction strategy currently pursued by virtually all countries of Eastern Europe and the former Soviet Union.

Eventually some groups have developed into broad and powerful movements and formally recognized organizations. Some other groups, however, chose

to remain small and informal and continue to address immediate issues and needs.

Membership of such informal groups and formal entities varies from a few individuals to a few hundred. Similarly, the diversity among members of these organizations is enormous – they include active and former drug users, members of 12-step groups, people living with HIV and other infectious diseases, prisoners and ex-prisoners, married and single, parents and future parents, physicians, journalists, politicians, and list goes on.

They all may be broadly described as likeminded people. They are committed to helping drug users to stop being victimized by law enforcement agents, to stop being treated like outcasts and criminals, to stop being denied much-needed health care and basic human rights.

It is essential to involve drug users in harm reduction projects. Their involvement could improve the quality of such services and make them more relevant and targeted. Besides, drug users may play a visible role in AIDS service organizations, in particular, those promoting adherence to ARV treatment. Beyond NGOs, drug users may be involved on an equal basis with others in various governmental, medical, law enforcement and other services, commissions, working groups, etc.

Activism is not limited to community-based actions; it is much broader, since the problems that users face affect every area of their lives. Once drug users realize that no one but themselves can solve these problems, once we begin to see other people around us facing the same problems, then and only then the problems may be solved. The battle has just started and victory is far away, but the first steps have been taken, and the effort will not be wasted.

***Your editorial team***







# Theorists: To the Right!

## Activism in Harm Reduction

*Why do drug users  
need associations?*

*Alexander Levin*

**Those who have worked with drug users since the 90s (mainly as part of harm reduction programs) and have been active in HIV prevention can tell you that terms such as advocacy, community involvement and mobilization have only recently entered our vocabulary. And it is only recently that they have started to make sense to most drug users in Central and Eastern Europe and Central Asia.**

What is behind these words? A while ago, discussions at training sessions and conferences focused mainly on expanding harm reduction services' coverage of drug users and on the ratio of used syringes returned.

At the same time, it was increasingly clear from informal discussions that prevention can be successful only where drug users are seen as partners, rather than clients, of the services. Avoiding HIV and death from overdose is not only a public health concern; it is primarily a personal concern of drug users themselves.

Historically, however, people who use drugs have rarely been included in discussions of issues that affect their lives. Marginalized because of their drug use and other factors, they have often been distanced from mainstream services, structures, and organizations, including harm reduction projects. Sometimes, the involvement of active drug users was limited to their employment in various positions within harm reduction projects, without the right to participate in decision-making – even though originally harm reduction ideology was founded on mutually beneficial cooperation between drug users, public health services and other players in this field.

**The Netherlands.** *Here people who use drugs have a long history of organizing. The Mainline foundation is an independent organization whose purpose is to improve the health and quality of life of drug users. Started by people who use drugs in 1990 as a small outreach program for HIV prevention in Amsterdam, Mainline has grown through the years into a professional harm reduction organization with national and international reach. Whether it's signaling trends in the world of users or stimulating risk-reduction behavior through the use of different methodologies, Mainline operates on the frontline.*

*Mainline forges a link between the world of drug users and that of doctors, medical personnel, aid workers and policy makers. Thus specialist knowledge is made available to drug users and the health risks run by users are examined and analyzed.*

**Canada.** *In 1997, in response to an emerging HIV crisis among people who use drugs and to government inaction, a few people from Vancouver set up a group of people who use drugs. This group eventually became known as the Vancouver Area Network of Drug Users (VANDU). It is the most active and largest of a number of drug user support and advocacy groups in Canada.*



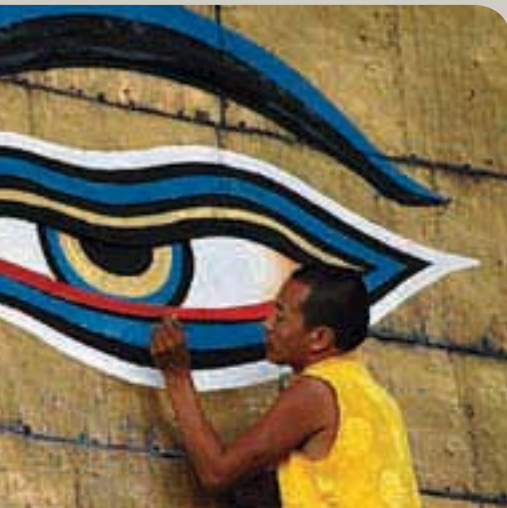
**Nepal.** *In this region, organizations of people who use drugs are particularly active in promoting health and social and establishing strong networks and groups:*

*Recovering Nepal is a national network of people who use drugs and drug service organizations in Nepal that has dedicated itself to the health, human rights and well-being of people who use drugs in Nepal since 2001.*

*The organization Aavash Samuha was established by drug users, the majority of whom are living with HIV/AIDS, under the motto “Nothing about us without us”. The sole motive of the organization is to provide quality harm reduction services and care and support services for drug users.*

*Richmond Fellowship Nepal has been working in the drug and alcohol field since 1997. They use a peer support approach in their rehab, as well as in a community based harm reduction drop-in and services in prison.*

*The National User’s Network in Nepal is acting to protect the rights of people who use drugs by seeking active involvement in all levels of decision making at the national and international levels.*





However, at some point many people realized that in a situation where harm reduction is pursued by public health and service organizations only, their institutional interests might prevail over those of drug users. As to the latter, no one except the community of drug users themselves will voice these interests or advocate for them.

This insight led to the fact that drug users are finally organizing, following in the steps of people living with HIV (PLWH), sex workers and others. It is taking place amidst the prevailing ethos of demonizing drug use. In some places, possession of a fraction of a gram of heroin is considered a serious crime, and drug users are denied their right to medical treatment and care. However, this work has now begun in Central and Eastern Europe and Central Asia.

Drug users, failing to find support from public health and other authorities mandated to respond to their needs, form associations in order to engage with government from a different perspective

and in a different way. Such engagement is mutually beneficial in all respects. Drug user organizing facilitates IDU involvement in programs, giving medical workers, social scientists and other professionals access to these “hard-to-reach” groups; it makes it possible to collect and analyze data for planning and evaluation purposes, etc. Since drug users are the beneficiaries, they can monitor and evaluate the performance of various services offered to them.

However, partnership is possible only where both sides participate on an equal basis and are interested in each other, not when one uses the other, even for good purposes.

### **Why is drug user involvement in harm reduction programs needed?**

The involvement of people who use drugs in harm reduction programs and other services that affect their lives is important for a number of reasons:

**First**, drug users make up a large proportion of people in our region who contract HIV, viral hepatitis, TB and other infections. Governments, service providers and health officials should be involving drug users because drug users are demanding it, and these services cannot have legitimacy if those they purport to serve are not in fact having their expressed need to participate met.

Moreover, there is a consensus among most public health professionals that there is an ethical obligation to involve PLWH and those at risk of HIV infection in programming. This is embodied in the Denver Principles in direct recognition of the structural causes of HIV transmission (criminalization, poverty, unaddressed mental health or other health issues, stigmatization, homelessness, etc.). Which for us is a reason to begin a discussion about involving users in these programs, and then about mutually beneficial cooperation and advocacy.



*"When I watch television, listen to the radio and read papers, I see and hear people say that the HIV problem has been solved in our country, and only a small number of people get infected. I find it ridiculous. They quote some figures, show us doctors and officials, but I know how it all happens in real life. And I know that the epidemic continues among my friends and acquaintances.*



*And it is not just HIV, but also hepatitis and tuberculosis. But nobody has done anything for these people. Nobody even knows anything about them. Maybe, this is the reason why things look so good on television."*

***Tatiana Semenova, drug user, Belarus***

**Second**, people who use drugs themselves are often best able to identify what works in their community – a community that others know little about. They need to be involved to create effective responses to the epidemic at every level – international, country, city, and neighborhood.

*“When I registered an organization of methadone program clients in our city, the situation with methadone provision here was catastrophic. The program lacked a psychologist, the dosages were wrong, and there were lots of other problems. It turned out that the doctors were not receiving any feedback and assumed that we were all happy with everything. Many clients were afraid to speak up, expecting some sort of repression, and some others found it easier to keep quiet because they were just too lazy to get involved in anything... Once we formed a group, we began by sitting down at the negotiation table with the doctors as equals. I cannot say that all problems have now been solved. But whenever something is not right, now we can talk to our doctors and let them know what exactly is wrong and what can be done to fix it. We are a sort of trade union. The doctors can see it, and they are willing to accommodate us.”*

**Marianna Iwulska, methadone program client,  
Liberation, Poland**

**Third**, drug users can make valuable contributions to their community, such as expanding the reach and effectiveness of HIV prevention and harm reduction services by making contact with those at greatest risk. Drug user involvement in harm reduction programs ensures the provision of much needed care and support to other members of the community, ongoing advocacy for their rights, and the recognition of their dignity.

*“It is important and necessary for an outreach worker to be trusted. His clients — drug users — must know that this person wants to help them. He works for a harm reduction project; he is not from their courtyard or from their neighborhood, but he does not want to create problems for the people whom he approaches. He just wants them to have fewer problems, not more. Therefore outreach workers should be in touch with the problem, and all of our outreach workers happen to be users or former users.”*

**Grigory Semyachkin, outreach worker,  
“Let’s Save the Future Together,” Moldova**

**Fourth**, there are ethical and human rights imperatives for involvement. As an ethical principle, all people should have the right to be involved in decisions affecting their lives. This fundamental requirement for meaningful involvement is consistent with the commitment made by governments in 2001 when they endorsed the UN General Assembly's Declaration of Commitment on HIV/AIDS. The Declaration calls for the greater involvement of people living with HIV and of people from marginalized communities in the response to HIV/AIDS.

### **Benefits of drug user involvement at the societal level**

People who use drugs should be able to influence local and national policies directly relevant to the problem of drug use in society, such as health care, crime prevention, and drug control policies. Their involvement sends a signal to society that people who use drugs have rights just like everybody, including the right to life, to health, to dignity, and safety. This awareness helps drug users to mobilize people into a potent political force for human rights advocacy.

*"There are two reasons why we are involved with a project for changing the drug legislation in our country. First, because our presence can help cut the red tape. Second, since we are working on issues facing drug users, it will help us address the problems from a higher level. Our involvement in the project is based on our desire to fight for human rights and freedom of choice, and to oppose discrimination in society and corruption in government."*

**Vitaly Melnikov, "Kolodets",  
Russia (quotation dating back to 2005)**





## Benefits of drug user involvement at the organizational level

Working with people who use drugs can help harm reduction projects to create more effective and appropriate services, to expand coverage, to improve the quality of services, and to ensure access to specialists.

*“From the very beginning, we have extensively employed active drug users as outreach counselors. It took me some time to stop being moralistic and judgmental toward drug users, but now I no longer lecture them on morals. Instead, I try to find out with the help of the outreach worker which of the problems faced by our client has the highest urgency at the moment, and then we work on solving this problem together. I believe that the collaboration of providers and users in the project helps them to overcome the barriers of misunderstanding and alienation and helps us to be more tolerant.”*

**Yuri Ivanov, harm reduction project coordinator, “Istok,” Russia**

## Benefits of drug user involvement at the individual level

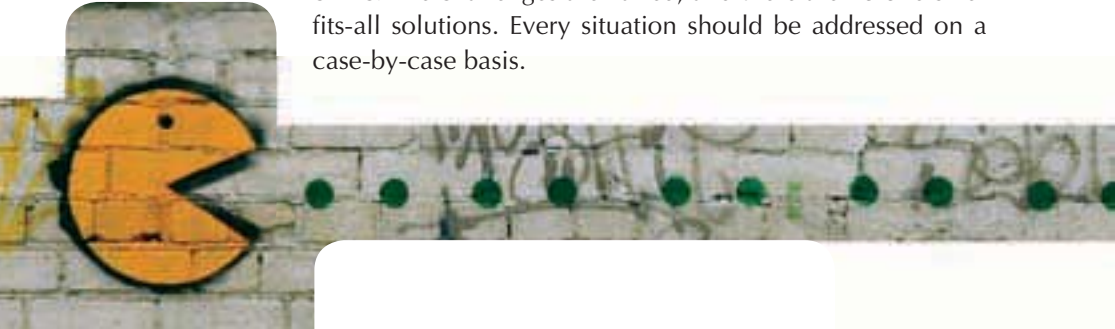
Becoming involved in harm reduction programs and community building also benefits people who use drugs themselves. Involvement in a regular and often salaried activity may support people as they are trying to find stability and purpose in their life, or improve their knowledge about diseases, treatment, and prevention methods. This activity may raise their self-esteem and expand the circle of acquaintances and specialists they can trust.

*“Before I started working for a harm reduction project I had been a client – an ordinary street drug user with all the consequences that go with it. Initially, people in the project looked at me with suspicion, and I was not sure whether or not I wanted [this job]. But today, after some time, I would be scared to lose this job. It is like a lifesaver for me. I find it interesting. I am doing meaningful work, even helping some people.”*

**Sergei Danilov, outreach worker, “Open Space,” Ukraine**

## Issues and challenges of user involvement in service programs

There are numerous issues and challenges facing drug users working in service programs and involved in drug user organizations. Basically, they face all the same problems as other users, i.e. they need time to find and buy drugs, their productivity and performance at work are affected by fluctuations in drug supply or purity, or by their ability to attend a methadone clinic. The challenges are varied, and there are no one-size-fits-all solutions. Every situation should be addressed on a case-by-case basis.



That said, there are many examples of organizations that have successfully employed people who actively use drugs. In general, managers of such organizations have decided that an individual worker's drug use is of no concern to them and do not focus on it. At the same time, they have workplace performance policies for being on time for work and meeting quality standards. If an individual's work is suffering from whatever cause, management will have a way of dealing with the problem, with the last resort being firing the employee.

*"Yes, being late, missing days from work, failing my responsibilities – all of this has happened to me on the job. However, I always try to warn my colleagues when I am having problems. I am against showing up at meetings when I am very drunk or acting inadequately. I do not approve of trying to get drugs when one works in a mixed team, i.e. an outreach worker and a non-using staff member."*

**Sergei Nefyodov, outreach worker,  
"Istok", Russia**

## Conclusions

Countries in Central and Eastern Europe and in Central Asia still lag behind countries such as the Netherlands, Australia, Canada, and others that have implemented an array of “low-threshold” harm reduction policies and programs. We need to remember, however, that back in 1990s just a few harm reduction programs operated in the region, subsequently giving rise to a network of projects and national programs for HIV prevention among people who use drugs.



The number and geography of needle exchange programs have been growing alongside political support for these prevention efforts. While substitution therapy is still prohibited in some countries, such as Russia, other countries in our region have made progress in this area, often due to coordinated and well-organized actions of the drug user community.

For example, drug users’ activism in Ukraine was a major factor in getting opioid substitution therapy (OST) with buprenorphine and methadone allowed, and in pushing the government and service providers to continue scale up. OST now reaches more than 4,000 patients in Ukraine and is continuing to grow, while OST patients have formed a regional network to advocate for their interests.

User organizing and mobilization have helped to link harm reduction efforts directly to the target communities and have empowered people affected by the problem to become involved in prevention and treatment efforts.

# Theorists: to the right!

## Keep up the Good Work, Kyrgyzstan!

*Notes on the life of drug users in a country  
where cannabis grows in most fields*

**Sherboto Tokombaev**



**Harm reduction began in Kyrgyzstan in 1999 with the opening of first needle exchange sites in Bishkek and Osh. By 2000, Kyrgyzstan was the only country in Central Asia with a needle exchange program in prisons, and by 2002 Kyrgyzstan was the first country in the Commonwealth of Independent States to offer methadone maintenance to opiate-dependent individuals.**

*From the report Pointing the Way: Harm Reduction in Kyrgyz Republic Daniel Wolfe, Center for History and Ethics of Public Health, Columbia University New York, NY USA, 2005:*

*“...In 2003, rehabilitation centers for drug users opened in Jalalabad, Osh, and Bishkek. While these are by definition drug-free, they maintain strong ties to and share staff with harm reduction projects, allowing patients who relapse into drug use to remain engaged in ongoing HIV prevention efforts...”*

How did it happen that a post-Soviet country with an Asian mentality adopted a liberal strategy? And who were the champions?

### **Who is responsible?**

Just so you understand the prerequisites that allowed the miracle to happen: Kyrgyzstan is a transit country for drugs from Afghanistan. What does it mean? Very simply, we have a lot of cheap heroin and opium available. Now let's remember our not-so-distant past: the punitive Soviet drug control policies, a legally mandated hunt for drug users resulting in huge prison terms. It used to be so much easier for police to fight the “narcomafia” in the Soviet Union: send a couple of addicts – weary from getting solutan in pharmacies and forging prescriptions for morphine and promedol – to prison; look the other way when you see youngsters smoking cannabis on the banks of Issyk Kul (canna-



bis grows freely there – no need for dealers to buy or sell it), and everyone is happy...

But all of a sudden, you can get opium everywhere. “Babushkas” sell morphine outside pharmacies, and the scary “imperialist” heroin is cheaper than a bottle of Absolute vodka. The old law continued to be enforced, and many people were sent to prison. In a few years the situation became explosive, with overcrowded prisons and corruption among police.

The ranks of drug users continued to grow relentlessly, gradually including family members and children of those who made and enforced laws. Kyrgyzstan is a small country; most people here are either neighbors or relatives.

***Sergey, participant of a harm reduction program:***

*“... In 2002, while in prison, I was diagnosed with HIV; before my conviction I had used drugs. I had heard about AIDS by that time, and I was not scared. Other diagnoses, such as hepatitis C or TB seemed much scarier to me. During my time in the colony I realized that it was much easier to die from dysentery than AIDS. I can see now that the most terrible thing is not the diagnosis, but the attitude of people around you who ostracize you from society because of their panic and fear of this disease. But no matter what, life must go on!”*

## **Stalkers**

When a few international organizations cautiously mentioned harm reduction for the first time, it created an instant resonance. Even government officials, not to mention civil society groups (to be honest, initially NGOs were staffed mainly by people from governmental agencies) championed this new approach.

**Alexander Zelichenko, PhD, police colonel:**

*"This was not an immediate "revelation." We made a few visits to other countries to learn from the experience of our foreign colleagues. There, for the first time, I saw drug users who were not like in our country – ready to do anything for a dose – but non-aggressive, non-criminal, even sort of "domestic" drug users. Soon I realized that their approach makes all the difference: in contrast to our country where drug users are "rolled into the asphalt," Western society does not treat drug users as criminals or drive them underground, but tries to help them return to normal life by offering them a variety of medical and social programs. And while we expand our prison population by sending drug users to prison, they [in the West] achieve success...*

*...I remember the shock experienced by law enforcement officials in our Republic when they saw a Dutch brochure titled "Protect Yourself: health advice for those who use drugs." The table of contents alone, including "10 golden rules of safer drug use; preparation of injectable solution; injecting methods; overdose; and a map of blood vessels indicating safer locations for injecting heroin" was enough for my colleagues to demand that the entire print run be destroyed immediately. It has taken international organizations and Kyrgyz specialists, particularly medical professionals and forward-thinking police officials, a lot of effort to change minds and approaches."*

At that time most new services were introduced. We should give credit to the people who were able to overcome their conservative thinking and to open up the way for new approaches. Unfortunately, however, it soon became obvious that without the ability to see the problem from the inside, all those beautiful and much-needed initiatives will remain on paper, in reports for donors and in presentations at international conferences.

The intentions were good: helping the drug users, their families, and the entire society. But the problem was that few people could really understand drug users. The common perception of the drug user community was very far from reality. Meanwhile, members of this community were dying from overdose as they tried to determine the dosage difference between their regular opium and the heroin that was suddenly available.



## Community

It all starts when a group of acquaintances come together to find solutions to their shared lifestyle challenges: how to stop injecting; how to be safe from HIV; how to solve your problems with law enforcement; how to restore identity papers. In the course of this activity a core group of leaders and activists emerges, as well as an understanding that finding solutions together is much more efficient than trying to do so alone. More people join the group – friends, acquaintances, and neighbors, friends of friends sharing the same problem or goal, inspired by the group’s success or seeking help. Usually the group leaders know where one can access clean syringes, detox treatment, legal assistance, “pure” drugs, methadone therapy, and many other things.

### ***Iskender, program participant:***

*“There is no difference whether you are an active user or “off drugs” at the moment. For example, I have been off drugs from time to time, and of course, when you are not looking for a dose, you have more time left for working in the program... Friends? Some have come off drugs, some have not, and I am on good terms will all of them, regardless...”*





## Just another step

In 2003, “Ranar,” the first organization of the drug user community, was set up. Such organizations are different from other NGOs active in HIV/AIDS prevention in that their members do not only share a purpose, but they also share their lifestyle, behavior and mentality due to the objective circumstances of their lives. For example, such groups operate almost round the clock, rather than from 9am to 6pm with a break for lunch, like most “official” NGOs.

Between 2004 and 2008, 11 such organizations formed the Harm Reduction Network of Kyrgyzstan (HRNK). Their members are directly affected by problems related to the epidemic and are highly motivated to promote their interests and ideas through advocacy work.

### **Bonivour Ishemkulov, HIV/AIDS specialist, “Potential”:**

*“...There are a few other arguments in favor of community-type organizations. These include: first-hand knowledge of the problems and their consequences; horizontal initiatives, i.e. priorities and solutions are determined collectively, without being imposed, without pressure or sanctions from any employer, and it makes a great positive difference for the outcome of such work. These organizations are driven by self-motivation. Their communication and outreach, and their activities and services for members of vulnerable groups are based on high levels of trust and take place in the target group’s territory. They know the people personally, names and nicknames, they use their slang, their codes, symbols and signs shared by this target group. Therefore they are much more efficient in getting information across, whether in oral or written form, than “official” NGOs. More groups of this type are being formed or spin off from existing ones, inspired by their friends’ stories, in neighboring districts or cities. They share the same interests and their ongoing communication is based on trust. They are known and trusted by virtually all drug users in their area and beyond...”*

## Taking action

The community members made an important contribution to the efforts of working groups engaged in preparing the Law on HIV/AIDS and amendments to criminal and administrative drug control policies. Advocacy efforts have led to changes in the criminal code, such as an increase of the minimum dose: now if they find up to one gram of heroin on you, you face administrative, rather than criminal liability; however, if they find drugs on you three times within one year, you will face criminal liability anyway. Thanks to the network's efforts, services such as substitution therapy, rehabilitation, and social support have been sustained.

Now, thanks to joint efforts of the HRNK and the Ministry of Justice of Kyrgyzstan, 10 penitentiary institutions have adopted social support programs for people released from prison. Today in Bishkek, drug user organizations are running a number of services, including a drop in center, a shelter for homeless people, community centers, social bureaus, and several programs for rehabilitation and re-adaptation.

### **Ravshan, social worker:**

*"... I am 36 years old, I have served two prison terms, and I have spent a total of ten years behind bars. But I am really lucky to have started my life anew, I have found new friends, and now I am employed as a social worker by a project of social support for vulnerable groups. Since I have been working for this project, more than 400 persons with various needs have accessed our social bureau. People like myself know and understand the needs of drug users released from prison better than anyone. These clients do not ask for much, they just need a few services, such as health care and referrals to detox, rehabilitation, or a methadone program..."*



One of the key objectives for the community is to engage effectively with the government and international organizations. Recent achievements include the involvement of a representative from the drug user community in the Country Coordinating Mechanism for the Global Fund grants, and representation of the community on the Steering Committee of AIDS Service NGOs in Kyrgyzstan.

It is possible today to speak on behalf of the drug user community at high-level meetings, and no one will care whether or not you currently use, what you have been using and for how long. The only thing that matters is what kind of person you are and what kind of professional you are, a situation one could hardly even imagine just five years ago when the label of “addict” was a lifelong stigma, regardless of one’s ability or professionalism.



# Theorists: to the right!



*A conversation with Dr. Leonid Vlasenko,  
narcologist who advocates alongside drug users  
for substitution therapy*

*Leonid Vlasenko,  
International Charitable Foundation  
“The William J. Clinton Foundation”*



**Kaleria:** *Tell me about yourself, what do you do?*

**Leonid:** I am a medical doctor; I completed my residency in psychiatry, and then I worked for various health care institutions in Dnepropetrovsk Oblast. My last position in the public health care system was that of chief medical officer in the Dnepropetrovsk Oblast Narcological Clinic. I have been working with harm reduction programs for about eight years; I was a co-founder, and currently I am Honorary President of the “Virtus” Charitable Foundation, an organization initiated by members of the drug user community and committed to promoting new methods of treatment and care and to removing the stigma of being affected by drug problems. In 2002, I came to work for a nongovernmental organization where I managed a harm reduction program, and then I coordinated a substitution therapy project. I completed a four-month internship in New York, with methadone substitution therapy programs. I then contributed to a manual on substitution therapy and was involved in research to evaluate the performance of the first pilot projects in Ukraine. For the past two years I have served as a regional representative of the William J. Clinton Foundation in Dnepropetrovsk and as a coordinator of integrated care services for HIV-infected IDUs. These projects run three sites offering methadone substitution therapy to three hundred patients, combined with additional consultations and social support. I have maintained my medical practice both within the NGO and privately (medical consultations and treatment of patients with addictions).

**Kaleria:** *How do you engage with members of the drug using community, and why do you think it is necessary?*

**Leonid:** I am convinced that the only way to reduce the negative consequences of drug use is to involve members of the user community in decision-making and hands-on implementation. Such involvement is about meaningful engagement of the user community members as equal partners with governmental institutions and NGOs, allowing them to mobilize the experience and expertise of the people directly affected by the problem in order to address the challenges faced in the health care and social welfare systems. “Virtus,” run by members of the user community and focused on implementation of a harm reduction project, provides a framework for such interaction to me personally. Also, I often talk to OST program patients, both individually and in group meetings. Such interaction is very useful. On the one hand, it allows you to raise awareness, explain and educate, and on the other, it provides you with essential feedback and other information that you cannot obtain in any other way – about developments on the drug scene, side effects of medications, social context, etc.

The internet provides yet another effective and increasingly important means of communication. In Ukraine, for example, there are two websites - [zpt.in.ua](http://zpt.in.ua) on substitution therapy and [motilek.com.ua](http://motilek.com.ua) on harm reduction – maintained by the user community. I try to contribute as much as I can by posting messages, answering questions, etc.

**Kaleria:** *Can you give examples of treatment-related problems solved thanks to this kind of cooperation?*

**Leonid:** The most important problem that is starting to be addressed is the provision of Addnok [the brand name of the buprenorphine used in Ukraine] to stable patients by prescription – allowing ‘take-home’ dosing. This option substantially decreases the stigmatizing effect of OST, positively influences the quality of treatment and increases the quality of life of OST patients. Prescriptions allow patients to obtain their medication in various pharmacies rather than in only one host clinic and that brings them social mobility. However, I do not think it would have been possible to break the deadlock on this issue without active involvement of the Association of OST Patients.

A pilot project of providing such prescriptions has just been completed, and we expect it to be scaled up.

**Kaleria:** *Can you give examples of personal and institutional problems that may arise from engagement with the user community?*

**Leonid:** The biggest problem is that of limited mobility of the community: many active drug users are dependent on their dealers and harassed by police, forcing them to limit their activity. This problem can partially affect OST patients: as long as you are in Ukraine you can be referred to a program site in another city, but you cannot legally continue OST if you travel to Russia or other countries.

Another problem that we face from time to time is a certain difference of interests between former IDUs in remission and current active drug users. This difference must be taken into account whenever joint activities are organized.

**Kaleria:** *How do you expect this engagement to develop in the future?*

**Leonid:** I really look forward to constructive future cooperation, and I hope that it will be facilitated by new and relevant harm reduction programs and evidence-based treatment options. Without the latter, the level of mutual trust and the effect of cooperation will be limited.

*Interview with Leonid Vlasenko  
by Kaleria Lavrova*



# Theorists: to the right!

*A conversation with Ekaterina Shakhnoze Yusupova from UNAIDS about modern methods of HIV/AIDS prevention*

*Shakhnoze Ekaterina Yusupova,  
Social Mobilization Advisor,  
UNAIDS*

**Kaleria:** *How does UNAIDS see the role of the IDU community in the HIV response in this region?*

**Ekaterina:** According to UNAIDS and national statistics from the countries of Eastern Europe and Central Asia, people who currently use or have used drugs make up a substantial proportion of the population in post Soviet countries who have contracted or are likely to contract HIV or viral hepatitis. The costs involved in the treatment of HIV and viral hepatitis, social support of infected individuals, prevention of secondary transmission to sex partners and mother-to-child transmission place an added burden on the emerging economies and transitional health care and social welfare systems undergoing reforms.

UNAIDS recognizes that people with drug using experience know better than others which forms and methods of working with their community would be the most effective ones, therefore their involvement is considered essential at all stages of design, implementation and monitoring of the response to the HIV epidemic among drug users.

Respect for human rights and greater involvement of people living with HIV and people from marginalized communities in the HIV/AIDS response are also called for in the “Declaration of Commitment on HIV/AIDS,” signed by the governments of many countries in 2001, and in the principles of “Greater Involvement of People Living with HIV/AIDS” (GIPA).

**Kaleria:** *How would you assess the current state of the IDU community in the region? What has been achieved and in what direction should community development proceed in the future? Do you know any examples of successful IDU mobilization and community development in any of the countries in this region, and any examples where the IDU community made a real impact on the HIV situation in the region?*

**Ekaterina:** People with drug using experience in countries of Eastern Europe and Central Asia have on many occasions demonstrated their ability to organize and to make a valuable contribution to their communities by improving the accessibility and performance of programs focusing on HIV prevention, harm reduction, social and psychological assistance, support for people at high risk of infection, and advocacy for rights and dignity. The involvement of people with drug using experience in advocacy – for example, the involvement of the “Kolodets” charitable fund in the work of the task force to reform the Russian drug policy in 2005 – facilitates the adoption of more humane policies toward people who use drugs. The involvement of people living with HIV in Country Coordinating Mechanisms of the Global Fund to Fight AIDS, Tuberculosis and Malaria, and in federal



and regional interdepartmental commissions for HIV/AIDS, facilitates the adoption of effective and timely responses to the epidemic and promotes a tolerant attitude among government officials, mass media and the general public toward people living with HIV.

**Kaleria:** *How does UNAIDS support the development of IDU community in the region? What programs are currently underway?*

**Ekaterina:** UNAIDS is engaged in active collaboration with the community of people living with HIV and with groups working to reduce drug-related harm to strengthen their institutional, programmatic, and financial sustainability and to build effective strategies for expanding the role of these organizations in HIV/AIDS-related decision-making. Organizations – members of the harm reduction network and organizations of people living with HIV – are involved in designing workplans, serve as co-chairs of HIV/AIDS Partnership Forums, and participate in national consultations on the progress toward universal access to HIV treatment, prevention, care, and support. Representatives of such NGOs have priority in being selected for participation in UNAIDS-supported training sessions and other events, and a board member of the Russian Harm Reduction Network sits on the UNAIDS Program Coordinating Board.

**Kaleria:** *What issues should the IDUs in the region focus on in the near future and in what way?*

**Ekaterina:** Efforts to support the leadership and activism of people living with HIV and having drug-using experience, to build the professional skills of people working in current programs, to strengthen the institutional capacity and strategic communication skills, plus effective engagement with other nongovernmental organizations, government, business and mass media, will enable community-based organizations to play a more significant role and to have greater influence on decision-making in the sphere of HIV/AIDS, social development, and policies affecting drug users. Raising financial support and using it efficiently will also ensure sustainable activity for the benefit of the community.

*Interview with Ekaterina Yusupova  
by Kaleria Lavrova*



# Practitioners: to the left!

## Representing People Who Use Drugs in Ukraine

*A conversation with Olga Belyaeva*

**Matt Curtis**

Although the first Eastern European drug user organizations appeared elsewhere, Ukraine has seen community groups flourish in recent years alongside improvements in the country's AIDS and drug services. From the beginning, people who use drugs had been involved in providing harm reduction services and other kinds of peer support. Especially with the introduction in 2004 of opioid substitution therapy (OST) – first with buprenorphine and later with methadone – people who use drugs began to find more opportunities for a safe space to develop more stable organizations representing their interests.

New activist organizations emerged representing a wide range of drug users' experience. Groups of people who use illegal drugs came together to fight for better access to harm reduction services and protection from police abuses. People receiving OST organized to provide peer support and advocate for the expansion of the country's OST system and improvements in how it was working. And people who had met in 12 step-based recovery programs formed a network to promote recovery groups as well as to advocate for the rights and health of all



people with an experience of illegal drug use. A national newspaper and online forum called Motilek ([www.motilek.com.ua](http://www.motilek.com.ua)) was founded by and for people who use drugs, and to this day reaches thousands of people every month.

By 2007, more than 20 organizations of people who used drugs had formed, and new opportunities for financial support, training, and networking were being provided by the Open Society Institute and the International HIV/AIDS Alliance in Ukraine. At that year's Ukrainian National Harm Reduction Conference, people who use drugs took the first step to demand a central role in all decisions affecting them, which was put forward under the slogan "Nothing About Us Without Us." Drug user activists organized a series of teaching events at the conference, as well as a protest at the conference opening which was reported on Kyiv and national television.

**One of the main organizers of these events was Olga Belyaeva, an activist and director of the harm reduction organization Virtus** in Dnepropetrovsk, Ukraine's third largest city. Olga was one of the first people in Ukraine to be accepted into buprenorphine therapy, and also one of the first to speak out about injustices in the system. She soon learned that although the program helped people a great deal, many problems remained in how OST services were delivered, and OST patients continued to suffer stigma and discrimination because of their treatment. In particular, patients were concerned about the requirement, still in force in Ukraine, that they attend their OST clinic every day in order to receive medication – a situation that means they are under virtual "house arrest," with no possibility to travel to another city to visit relatives, participate in meetings with their colleagues, or take advantage of other opportunities.

Patient activist groups began to demand that take-home prescriptions of buprenorphine and methadone be allowed, and Olga's was a frequent voice in advocacy. In 2008, along with activists from 13 cities, Olga began to form the Association of Substitution Therapy Adherences of Ukraine in an effort to

unite the thousands of people now on OST in Ukraine to fight for their rights. Olga became chair of the Association's board of directors, and began working to identify and train local organizers all over the country.

Recently, I spoke with Olga about her life, the Association, and how she became involved in working for the rights of people who use drugs.

**Mat:** *Tell me a bit about yourself and how you originally became involved in this work?*



**Olga:** Olga: How it all started... I am Olga Belyaeva. I was born and I live in Ukraine, the city of Dnepropetrovsk. I went to school, then to college. Then I worked as a dental technician, a driver, a salesperson, and set up a private business. It was my search for my place in life. A search for my own way to be happy to go to work and happy to come back home after work. For 22 years there were drugs, music and books. Many books: Hesse and Dostoyevsky, Castaneda and Borges, Haruki Murakami, and other great authors.

My life is about happiness and harmony. I live to make the world a happier, friendlier place for every human being. I had tried to do so working for government and trade unions, but the system and its bureaucracy always raised a barrier between me and a person who comes to me for help. Then I approached businesses, but the business people refused to donate to drug users, because it was bad publicity.

Then I had an idea of setting up a Charitable Foundation. At that time I met Dr. Leonid Vlasenko, narcologist and psychiatrist, a man strikingly different from many of his colleagues by being very gentle, caring, and understanding.

**Matt:** *How did you first come to understand harm reduction?*

**Olga:** In 2001 there were no needle exchange programs for drug users in Dnepropetrovsk. I was just beginning to learn about the harm reduction philosophy. Once during a meeting with representatives of various government authorities our foundation was offered syringes and asked to set up syringe exchange sites.

I remember our very FIRST syringe exchange site with a smile. I drove into a courtyard, arranged the hand-out supplies beautifully on the hood of my car and began to invite people who used drugs to come over and take a free syringe. And although most of them knew me personally, their first reaction was that of surprise, shock, and confusion.

And what would you expect? Just imagine that where we live any medical or social assistance is provided to drug users on condition of giving up drugs. We are always forced to make this choice and to become the sort of person that the organization with resources to help us would like to see. If it is a religious denomination, you are required to come off drugs and practice their faith; if it is a governmental agency, you are required to come off drugs and pay taxes...

People would come up to me and ask, what are we required to do? What do you mean nothing? What do you mean just to keep me healthy? Do you care about me?

I particularly remember one story from the times of our first syringe exchange site. After I have exchanged all the syringes provided, the Family and Youth Center that had supplied the syringes sent their people to monitor us. They wanted to inspect the flats of drug users where the secondary exchange was taking place.

Before their monitoring visit I went to one such flat to ask the woman who lived there whether I could bring some people along on the next day. The flat owner, Natasha, around 35 years old, who engaged in sex work to earn money for drugs, did not normally have time to clean up, so her place looked like what most people would describe



as a drug den: sofas stinking of tobacco, dirty clothes strewn around, syringes, ash-trays, old blankets over the windows. I was surprised when Natasha immediately agreed to have people over.

The next day when Natasha opened the door to the people from the Family and Youth Center and to me, I was filled with wonder and amazement. The woman in front of us was wearing an evening gown (borrowed from her mom), carefully styled hair and makeup. The flat was in perfect order and shining clean.

I looked into Natasha's bright eyes and realized that she was happy to be in the center of attention, to be interesting to other people. I do not remember the moment the inspectors left, but I remember that I stayed with Natasha in her flat and we spent quite a while just sitting silently next to each other, crying and quietly sharing our little secrets. It was the beginning of my harm reduction philosophy...

**Matt:** *And that is when Virtus really began to grow. Can you speak about that a bit?*

**Olga:** We offer people an opportunity, but we do not force them to make a choice. It has attracted people to our foundation named Virtus – translated from Latin as courage, responsibility, moral virtue.

Over the eight years, more than 3,000 people who use drugs have become part of Virtus. The foundation employs professional providers of social, legal, psychological, and medical services, with specialist training in harm reduction, who for the most part use drugs themselves.

And I insist on describing our staff in this order: first come their professional skills, and then their personal choices which help them in their work.

**Matt:** *You started taking substitution therapy a couple years ago now. What was the experience like at the time for you?*

**Olga:** Since 7 November 2005, I have lived legally, because I have been taking substitution maintenance therapy with buprenorphine. What it means for my

family and me? It means stability, calm, health, ability to care for each other, to talk to my son in the evenings, and to get rid of a persistent feeling of being useless.

Our medical profession, however, was unprepared for this type of radical change. Narcologists were instructed in the medical school that their goal was to separate the person from the drugs. But here we have an entirely different story. Therefore substitution therapy programs arrange ongoing training for health professionals and social workers on their staff.

**Matt:** *And thus the Association... Tell me about it, why do Ukrainian OST patients think that the Association is needed now? How did the Association begin to be formed?*

**Olga:** It is July 2009. We are looking forward to the birth, i.e. official registration of an Association of Ukrainian OST Patients. And although only OST is mentioned in its name, we invite all drug users, both legal (OST) and illegal; all people who share the Nothing About Us Without Us manifesto and believe that everyone's personal involvement can make our country and the entire world a more friendly place for us, people who use drugs.

We have joined forces to set up a strong human rights network. We will get our lawyers to be available via a 24-hour helpline, prepared to go out to any city in Ukraine in response to violation of the constitutional rights of any member of our Association. To achieve this, we will charge a membership fee and hire the best human rights lawyers. Another activity will be advocacy for harm reduction and OST programs as part of the overall philosophy of providing adequate care to people using drugs.

In 2009, we plan to get buprenorphine dispensed by prescription and to get Order No 360 of 19.07.2005 amended to allow methadone to be available by prescription as a take-home medication. We also want each OST site to be accessible seven days a week to make the therapy available on weekends and holidays. We have set ourselves lots of objectives, which you may look up at [www.motilek.com.ua](http://www.motilek.com.ua).

**Matt:** *It's already been five years since programs of substitution therapy started in Ukraine. Many people have been very hopeful that OST would*





*expand quickly and have a big effect on problems related to drug use and HIV, and to also be an inspiration for neighboring countries. Looking back on these five years, how do you think it's gone? What's your overall assessment of substitution therapy in Ukraine today?*

**Olga:** Today we are more than 4,000 people receiving OST from 92 sites in Ukraine. But we in Ukraine have not met our commitment to the Global Fund, because our country had promised to have 6,000 on OST before 01.01.2009. Why didn't it happen?

We have many people on waiting lists, we have hospitals ready to take patients, but these hospitals are not on the Ministry of Health list. There are problems with OST logistics and redistribution. I believe the main problem is that our legislation lags behind our programs, and that OST programs are not integrated in the mainstream health care system in Ukraine.

However, the effects and the benefits of OST are obvious. Adherence to HAART has increased among drug users, and 387 people in OST are currently (01.07.2009) on HAART. A total of 1,879 participants of OST programs have tested HIV-positive, which means that they know their own CD4 and viral load and are monitored by specialists.

*Interview with Olga Belyaeva by Matt Curtis,  
independent harm reduction activist*



## The “Mozg” Magazine

*A Report from the Field  
by Humanoids*

*Andrei Ufo (one of the first authors  
of Mozg and PG)*

*Place of origin: Moscow. 1999.*

*Chisty Prudy – Lubyanka.*

***Editorial reflections on the origins of “Mozg” –  
a magazine about harm reduction:***

The idea came about when I was struck by what I saw in Lubyanka [a square in Moscow, famous as the location of the KGB headquarters], where I went with my friend from childhood, who was using “vint” at the time and hoped to buy a lifesaving bottle of solutan. I was a journalism student then and, of course, would rather try to save humanity than waste my time sitting in the classroom or smoking weed during breaks.

At the time, drug dealing around Lubyanka was at its peak . A visitor could see “babushkas” – supervised by police – selling solutan and ketamine outside Pharmacy No 1, groups of homeless children sniffing glue in dark alleys, and heroin users cooking their stuff in the entrance halls of nearby buildings. When you are 20 and an aspiring journalist, seeing your friends do drugs and die is a good enough reason to publish a magazine to tell them in a straightforward language how they can protect themselves, because they are likely to trust you, even though they would not trust cops, narcologists and other dumb-ologists.

This idea was what eventually brought about the magazine.

It so happened that my urge to help my friends coincided with the launch of a harm reduction project by MSF-Holland. It was only natural for participants of this project to get involved in the publication. So I contacted them and suggested we give it a try.

Why we opted for a magazine, rather than a newsletter, a book or a small booklet on cheap paper.

All young intellectuals then wanted to produce their fanzines – and drug users also wanted their own publication. This is how “Mozg” [“Brain”] came about with support from the Dutch organization Mainline, one of the oldest associations of drug users in Amsterdam producing a publication with the same title. The first issue carried

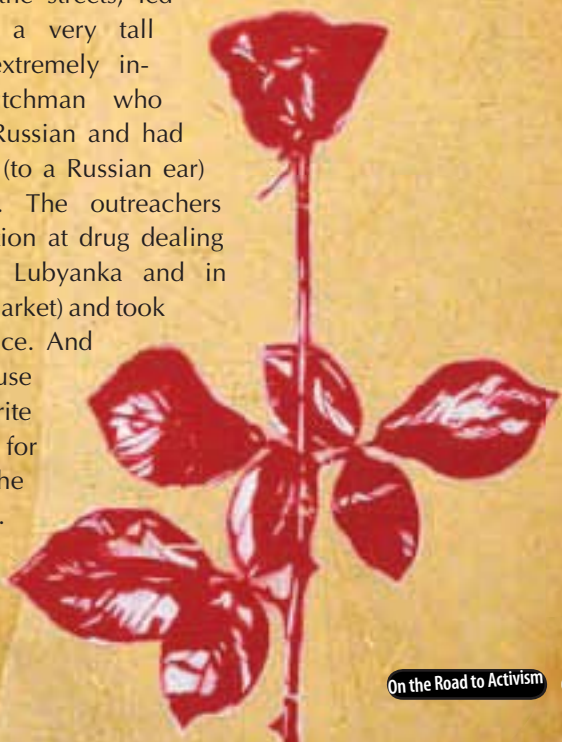
a few translated articles from Mainline - also as a sign of appreciation. And then we produced our own articles thanks to ten social workers who could not understand a word of English and did outreach in the streets, led

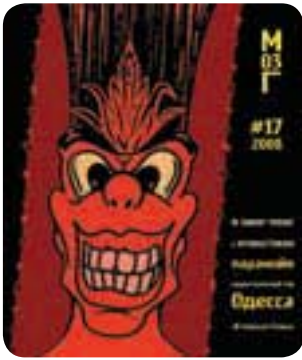
by a very tall  
and extremely in-

telligent Dutchman who could not speak Russian and had the odd-sounding (to a Russian ear) name of Murdo. The outreachers collected information at drug dealing spots, mainly in Lubyanka and in Ptichka (the Bird Market) and took it back to the office. And

then we would use this information to write brochures and articles for the magazine, and take the magazine back to the streets.

Alik Khachatryan was editor-in-chief, and I was what they





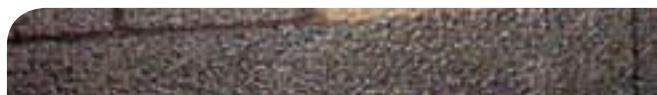
call in big magazines a managing editor. Our magazine was produced in this manner for two and a half years, until MSF-Holland terminated their HIV project in Russia. By that time, the magazine had grown into an independent and – should I say? – iconic publication for its audience. It had begun to cover more advanced topics, and alongside stories about the effects of ketamine, harvesting trips and prison adventures, we published articles about drug legalization and decriminalization, substitution therapy, rehab programs, community organizing, direct action, flash mobs, cultural projects, and others... phew, I am short of breath after such a long list. And equally important, it has always been – and remains – an art project created by and for those who use various methods of changing their consciousness.

The newly established Charitable Foundation for a Healthy Society agreed to support the publication, and the author of this text became its editor-in-chief.

Here are some of our friends and contributors: “Kolodets,” a self-organization of drug users; Ptyuch, magazine and club; artist Andrei Bartenyev; organizers of the annual “Kazantip” festival; Lev Levinson, human rights defender; Dmitry Gaiduk, writer and storyteller; “Caribace” dub group; “Griboyedov” club (St. Petersburg); “Medical Hermeneutique” art group; “Rechniki”; poet Alexander Delfinov and “PG” group, and many others – I will take too much space if I try to list all of them.

Then for eight years the magazine was produced at irregular periods with support from our Ukrainian partner, the International HIV/AIDS Alliance, and distributed in Russia and Ukraine. As time passed, the magazine changed, as well as its authors, and by the time of our last paper-based issue we had decided to expand our audience beyond the original subculture. Currently, the magazine is published online at [mozglab.ru](http://mozglab.ru)

***Editor-in-Chief, “Mozg” Magazine  
Ekaterina Kotova  
April 2009***



## Cast No Dirt into the Well ("Kolodets")

"Kolodets," a drug user organization, grew from a self-help group. It all started when in the summer of 2001 at a certain day and hour a group of people got together in Moscow, because they needed to talk and to solve numerous problems related to drug use. After a while, active members of the group decided to register it as a "Kolodets" Charitable Foundation and focus on providing social support and rehabilitation services to people



who use drugs via self-help group meetings. Members of the community intended to address the health issues faced by drug users by engaging in advocacy for access to health care. And of course, by working with mass media to change stereotypes and promote a better attitude in society toward users of psychoactive drugs.

In an attempt to make a statement and to draw attention to problems faced by the community, “Kolodets” chose the method of direct actions, such as planting trees in memory of people who died from drugs; a rally for the human rights of Thai drug users; a Cannabis March for legalization of marijuana, and many others.

On 16 December 2003, new amendments of the Russian Criminal Code substantially modified the provisions for drug-related criminal liability and punishment. The amendments came as a result of almost seven years of efforts, in which the New Drug Policy Alliance, a new civil society initiative for Russian drug policy reform, had played a major role. In 2003, “Kolodets” joined the Alliance as a full member, alongside the Human Rights Institute and the Charitable Foundation for a Healthy Society.

In the Alliance, “Kolodets” contributed its expertise in drug-related issues on



many occasions. In particular, the newly adopted average daily doses [as a criteria for establishing criminal liability] were based primarily on feedback from drug users, collected and communicated to legislators by “Kolodets.” It was an important factor in the success of reform, because advocates for the new legislation could argue that the proposed doses reflected the actual situation and were based on data received from the drug user community.

Once the new average daily doses were approved, many criminal sentences were revoked, and more than 35,000 prisoners were released. Unfortunately, in 2005 the drug legislation was amended again to make it tougher. It had a negative effect on the Russian drug policy, taking it back to the times of “war” against users.

Facing a new situation, “Kolodets” continued its fight for human rights and freedom of choice and against discrimination of drug users in society.

After a while it became clear that advocacy for substitution therapy in Russia should take place at various levels. “Kolodets” took up the challenge and set up a working group of representatives from “friendly” organizations to meet and discuss the most pressing issues. At the same time, the organization produced brochures and books, published articles in mass media, organized press conferences and maintained a mailing list.

During the same period “Kolodets” started to offer case management services to drug users, including former prisoners, HIV-positive people, pregnant drug users and many others who needed help, but for some reason could not access it. The case management service enabled them to get a job, to restore their identity papers, and to access medical care.

At the moment, “Kolodets” is not active, but that does not mean it no longer exists. Even though the former team has left the organization and new people have not yet come around, they may show up in the future.

*Alexander Levin*

## Remissioners!

*Remissioners seven years later*

In November 2001, a few creative people met at a Moscow flat for the first time, each of whom had significant personal experience with both drug use and coping with drug use. The result of this meeting was a decision: to organize a long term creative campaign called “Remissioners” in order to change public attitudes towards people who are users or ex-users of illegal substances. Drug user: not just the same human being, like any other, but in some cases a talented person.

“Remissioners” released a book of the same name, which, in addition to already well-known authors such as Yegor Radov and Dmitry Hayduk, included beginners, mostly who had published their texts on the Internet at clubbers’ resources like VintClub and DrugUsers.ru. Later, they also released a second book named “Bees against beekeepers”. In addition, “Remissioners” organized the festival “Rock against Narcologists” to draw attention to the issue of commercialization and charlatanism in Russia’s drug addiction treatment system.





It feels like a lot of time has passed, not just seven years or less. Probably we feel and think so because these seven years have been so intense, with real personal growth and transition to new modes of thinking, awareness and balance. What I and many others wanted back then was a righteous battle, crowds of like-minded people, manifestations, exposure of villains and enemies. By now we understand the priority of peace and harmony in your soul, heart, liver, and speech. But back then – seven years ago – we had fun. We failed to see the coming deaths of our friends and acquaintances. We were not aware that something we are enjoying might come back at some of us in a mask of terror. The only reason that helps me forgive myself now is that we were sincere. To be sure, we wanted fame and were convinced that we were doing something extremely important. Pride? Of course... But at least it was balanced by the fact that none of us was motivated by money. I hope that *Remissioners* will remain in people's memories as something driven by altruism, inspiration, fantasy, youth and excitement. And I also hope that it will remind us of those who left our physical dimension too early. Rest in peace Gleb Olisov, Yegor Radov, Dima Burlaka and Kostya Kotik from the Lam Bops group...



If an idea to create something similar to *Remissioners* occurred to me today, I would let it pass. Not only because it has already been created. Most importantly, I now have a new and more sober perspective on certain things that then appeared unquestionable (those who questioned them were dismissed as dumb losers). This was our unavoidable youth maximalism.

Nevertheless, we were able to stir the stale and stinking waters of Russia's commercial narcology of the early 21st century and to get many really talented people involved in our common cause. We produced a couple of books that are rarities by now. Print media wrote a lot about us, and we were even on television occasionally. Unfortunately, after the campaign nothing happened; no one was inspired, no one was really helped. We should look at ourselves – not at those who deserted us – for causes of this infertility. Our slogans and declarations differed so much from our own lifestyles that, perhaps, God could see our inability to go further and stopped us halfway.

Exposing narcological crooks and medical quacks, we had fun mixing what should and should not be mixed together, and treating one another quite unceremoniously. The action was possible only because nothing of the kind had been attempted in Russia before.

Even now I cannot understand why the Central House of Artists agreed to host us, and why our press conference attracted the leading narcologists from Moscow and even from St. Petersburg for good measure. Not to mention the funding for our two books – it is still a mystery to me. One of the two books was financed by a narcologist, and the other by someone who had asked to give him credit by mentioning his name as the producer of our action. It was nothing short of a miracle. This so-called producer also supported the music festival: he served food to the performers while they were waiting for their turn to perform, he served drinks to those in real need, and convinced the administrators to allow the concert to continue after the agreed time. The book financed by a narcologist named Vladimir had the same title as the action: *Remissioners*. The book financed by the “producer” was titled *Bees against Beekeepers* and was published to coincide with the closing event of the action, a five-hour concert Rock Against Narcologists. The “producer” invented the titles of the festival and “his” book, and the title for the entire action was invented by Bayan Shiryanov.

Many participants of the project have since disappeared – at least, I have not heard from them. I do not know what has become of the Yaga-Jaga group – some of the performers were Africans and they played excellent reggae music. Maybe, their music did not catch on with an audience that preferred cheap versions of hip hop. Lam Bops are doing fine. They have produced an album and sometimes they perform in clubs and at festivals, punk rock as always.

The *Maluta Skuratov* group performs quite often, while Misha Ardabyev who had inspired this 90s radicalism writes good poetry and very few songs. I am not sure what Dima Gaiduk has been doing over the last couple of years; our cooperation was very productive at the time, but then we suddenly parted ways. *Remissioners* would have been different without him. He is about ten years my senior. It hardly matters now, but it did matter then. Dima did not only edit both books, but he had really put them together by

bringing in good authors and continuously restraining my excessive and misplaced zeal. Andrei Rodionov is a well-known poet now, he has received some awards and has been traveling around with readings of his poetry; he has three kids, just like me. Alina Vitukhnovskaya lives a complicated, but interesting life. She writes and speaks a lot and she has not stopped fighting windmills. I do not know how Irina Shostakovskaya is doing now, but I am convinced that she was one of the biggest stars of the action, and the light she shines deserves the highest praise. We have preserved distant, but warm relations with Seryozha Sokolovsky. He is now also a writer, editor – in a good sense – and participates in some nice projects. Max Dubinsky has turned a new leaf: from rebel and outcast he has transformed into a respectable descendant of well-placed parents. Ubik, AKA Vlad Osovsky, continues to write beautiful short stories, and his life continues to resemble a rollercoaster. It is difficult to mention everyone in a short article: there were about 50 participants. But I will spend some time writing about one of my friends – not only to honor his memory, but also to wonder at how huge and powerful his presence is, even though he is not with us anymore for at least three years.

### Gleb Olisov!


Some people insist on defining him as a writer. To be sure, he has authored a few now-iconic short stories and a couple of incredibly moving screenplays. But Gleb, or Dis, as close friends and family called him, did not have time to become a full-fledged writer. The fact that he left before he had a chance to become part of the oppressive world may be a good thing. He remained the idealistic, somewhat melancholy and always sincere Gleb, my friend who did not live long enough to break down and become like some other people who forget what it means to be a child.

A few years before the action, then a drug user in his early 20s living in St. Petersburg, he created a website – the Russian Vint-Club. Even at that



time it was an unheard-of and extremely daring act. One can hardly understand from the current perspective what it was all about. There is no such freedom now. The country was breaking apart; centuries-old barriers were collapsing. Thousands, millions of young people with bruises from injections on their arms and legs were learning how to inject into the femoral vein – and their parents had no clue. Sometimes I suspect that





Russia's big cities were flooded with drugs by someone's plan to contain the huge wave of crime and banditry rising in the suburbs of major Russian cities in mid-90s. How? By supplying the idle, alienated and totally ignored youngsters with something that would give them euphoria. The method was quick and easy, inexpensive and reliable. Besides, we should not rule out Afghanistan's revenge for the occupation described by the Soviet authorities as our "international duty." As the collapse of the last century's last decade was coming to an end, Gleb Olisov appeared with his Vint-Club, later leading to *Remissioners*.

### The Russian Vint-Club

When I first hit the Club's website, there were 30 or more visitors there, discussing various problems of our risk group against a venomously violet background. Someone had blood clots in his arms; someone wondered if he could cook his stuff using a new pharmacological substance; someone else was in withdrawal and just needed to talk. I brought along a newly written book – *The Street Circus of Working Class Neighborhoods* – where half of the characters were drug users.

The book was welcomed by the local subculture and praised even by Bayan Shiryanov, one of the oldest leaders of the crowd. Very soon we were all good friends. The drug users turned out to be amazing young personalities! In ten years I have not seen a website in the Russian internet with such a bright crowd. It is not surprising that half of the original core is no longer with us. The most recent funeral – just a month and a half ago – was that of Ilya Futur.

Every time one of the guys was carried to the cemetery, all of them appeared before my eyes, and the first of them Dis himself, who had brought us all together in one place and had simply helped us survive. The Russian internet was very different ten years ago. The TV heads were not even aware of its existence, and some rare articles in print media argued between themselves whether the internet had a future. The Russian internet was "cleaner" at the

time, because there were fewer people and those who showed up on the web were interested in reaching out to the entire world in search of likeminded individuals. “A place for likeminded people” was the slogan of the Russian Vint-Club.

Dis, as the administrator with dictatorial powers, encouraged creative efforts of the “comrades” as we addressed each other (the practice was started by Dima Goblin, now a famous interpreter of popular foreign films). The Russian internet was a single organism at the time, everything was intertwined, and people would register at newly launched websites all at once. Those who did not see the beginning cannot even imagine how it was.

The informational sponsors mentioned on Remissioners’ ads were AiF, the Russian Vint-Club and Udaff.com. It was from the Vint-Club website that we called for literary contributions to our first book. The news spread all over the Russian internet, and soon Gaiduk and I began to receive manuscripts, most of which did not make it to the book due to lack of space, not because they were not good enough.

The book *Remissionaries* began with two tragic and powerful stories by Gleb Olisov titled *Tanya Is the Last One Left* [in reference to a note left by a girl who was the last one left of her family who died of famine during the 1941 siege of Leningrad]. Dis, born in Leningrad, wrote a story of deaths in his city in the 90s. His *Tanya* sounds like a verdict to that time and to the regime reigning on the post-Soviet space. What Gleb wrote was not just a manifesto, but also an example of the kind of writing we want today.



Currently, Drugusers.ru is a site where any advertising of drugs and methods of their preparation is strictly forbidden. The site attracts not only users of stimulants, but also those who prefer using stuff to slow down, and those who drink alcohol (currently I am one of them), codependent wives and other relatives, and a lot of other unexpected people who visit the site to learn how to deal with their own addiction, how to help someone who is suffering, how to behave around a beginning drug user to avoid harming him or her.

The site today has three forums about creativity. Someone who would wish to publish a book may find enough material for two volumes, but where would such a person come from? We used to be altruistic, committed to the cause.

The new generation is more rational and focused on grant opportunities. Everything begins and ends with a budget. But we did not even know the term. We were just doing what we wanted and sincerely believed that we were helping people to hang on and resist the depressing environment.

Today almost all of the surviving comrades – as we continue to address one another – have stopped using substances and even if they use something sometimes they do it in a different way. We can even say that Remissioners and the Drugusers.ru website offer a good argument for why one should not submit entirely to substances, however magical their effect may seem. Amen.

**Aleksey Rafiev**



## Practitioners: to the left!



### Front AIDS on the Barricades

In 2004, while countries throughout the world had begun to take steps to make HIV treatment available, in Russia, the medicines were available only to a select few and people who use drugs (who comprised the majority of those living with HIV in Russia) were systematically excluded from treatment. Government authorities and even most civil society organizations seemed complacent with the status quo in Russia. In that year, a group of like-minded activists and people who use drugs, people who felt Russia's status quo as something more than fresh statistics in a new report but as something that was taking the lives of their friends and loved ones and something that embodied great injustice, came together to form FrontAIDS.





**Andrey “Irokez” Rylkov**, one of the founders of FrontAIDS and one of Russia’s leading harm reduction activists, a champion of the rights of outreach workers, and a person with keen sense of social justice, helped bring together people living with HIV, people who use or formerly used drugs, and even activists from other spheres.

The first FrontAIDS meeting decided that whenever authorities denied citizens their legitimate right to know the truth about the situation with HIV/AIDS in their country and the right to demand compliance with existing laws, the organization will engage in direct (unsanctioned) actions.

FrontAIDS members believed in their right to such actions, since people must defend their right to life using all means available to them, including protests, marches, and other public activity. Everybody realized that the time for such action had come, and within a short period multiple actions were organized in Kaliningrad, St. Petersburg, and Moscow.

### **“Our Deaths Are Your Shame”**

The first action was organized in Kaliningrad: on 12 October 2004, 20 activists handcuffed themselves to the doors of Kaliningrad city hall, blocking the entrance. The protesters were taken to the police precinct and fined. But the following day representatives of the city administration invited them to negotiations. All of the local and many national media outlets covered the action and explained the desperate situation people with HIV faced in Kaliningrad. Kaliningrad is considered the city where the Russian AIDS epidemic began.

### **“While You Are Talking We Are Dying”**

The second action was held in St. Petersburg on 9 November 2004. St. Petersburg was second only to Moscow in numbers of registered HIV cases.

When the organizers notified the authorities about their plans for a rally, their request was turned down without any justification, so they went ahead with an unsanctioned rally, which involved more than 50 people placing four coffins directly in front of the Smolny building—the seat of the St. Petersburg government. The St. Petersburg authorities turned out to be more lenient—only one activist was arrested—but unfortunately also less sympathetic. None of the officials agreed to meet with the activists. Nevertheless, the action was widely covered by the media.



### **“We Will Live – That Is Our Policy”**

The third protest was a rally in front of the Russian White House – the seat of the federal Government in Moscow. It was sanctioned by authorities and held on December 1, World AIDS Day. The protesters hung a huge, 600 sq. meters banner with the FrontAIDS logo and the words “Our Deaths Are Your Shame” from a bridge over the Moskva River that faces the White House. The protest lasted for about two hours; even though it was freezing cold ( $-15^{\circ}\text{C} = 5^{\circ}\text{F}$ ), around 400 people joined the rally.

A few more direct actions were held later, with broad resonance in mass media, government and society. It was a response to the government’s indifference to the fact that many young people faced their deaths due to the absence of antiretroviral treatment and appropriate

medical care. Direct action was also designed to attract attention to the desperate situation of HIV-positive people who used drugs and were usually denied treatment under the pretext that they were not capable of adherence.

Within a year of the demonstrations, the Russian government increased funds allocated to HIV by 20 times, becoming one of the first of the former Soviet countries to allocate significant national funds to HIV, including treatment. There were many factors that led to this change and FrontAIDS made an important contribution.



## Passage in Macedonia

Macedonia is one of the few countries in Eastern Europe with substitution treatment programs. Their operation now relies on the activism of their clients, which is related to the emerging drug user movement in the country. Drug users in Macedonia took their first steps toward building an association in 2002-2003.

“It was a moment when many of my friends could feel that the time was right. Important decisions about drugs were being made. We realized that in order to influence the situation we had to act promptly or face decisions made for us by other people who have nothing to do with the issue,” says **Vito Georgievski**, leader of drug user organization **Passage in Macedonia**.



The group's first initiatives were designed to improve the services available to OST program clients, and to defend the rights of these clients. Initially, OST programs in Macedonia faced serious difficulties.

"To begin with, local municipalities in Skopje, the capital of Macedonia, would not permit the programs to operate. At that time it was easier to scale up OST programs in prisons than in the city. In fact, more people wished to access the programs than there were slots available. We still have waiting lists, and people wait for a long time to be admitted to a program. Another problem is that doctors prescribe inadequate OST dosages, so the clients continue using illicit drugs," says Vito.

Passage, formally registered in 2007, also advocates for appropriate drug policies. Last year, a bill was launched in the local legislative assembly in Macedonia. The bill would introduce the same criminal liability for drug users and drug dealers. Passage organized numerous actions lasting a





whole week, including a rally outside the parliament building, roundtables with drug users and drug policy experts, and meetings with journalists. Mostly as a result of the actions and the broader campaign organized by Passage, the bill was rejected and sent back for revision.

“Also, our organization has been pushing for the opening of an OST clinic for 400 people in Skopje. There is money for it from the Global Fund. But due to red tape and, apparently, unwillingness of the local authorities, nothing is happening. If the money is not spent before the end of this grant period, the money will have to be returned to the GF, and 400 people will be left without the help they need. We believe that as long as it affects us directly, we must do our best to find a solution,” said Vito.

As a result of these efforts, currently there are two OST centers, that offer treatment for drug users across Macedonia and both are located in Skopje, where 2/3 of Macedonia’s population of drug users lives. Center in Kisala



Voda involves 400 clients and has the staff of 6 doctors, 2 psychologists, 8 nurses and 2 social workers.

In July 2009, a new OST clinic was opened in Skopje. After a long delay it was opened within two weeks time and in the end of September hosted about 90 people, clients of opioid substitution therapy. “We are still waiting for opening the third clinic which to be honest I don’t believe that will happen very soon, as situation remains very complicated”, said Vito.

An important event in the life of the drug-user community last year was a tree-planting action in the memory of drug users who had died; 80 trees were planted. As an organization of drug users, Passage has been focusing on community development by organizing meetings and conferences for activists from other cities and districts of Macedonia and from other countries. People attending the conferences spend time together, share their experience and address current problems.

*Aleksandr Levin*



Part Three

# Stand Still! Count off! We Are All Caught in Networks



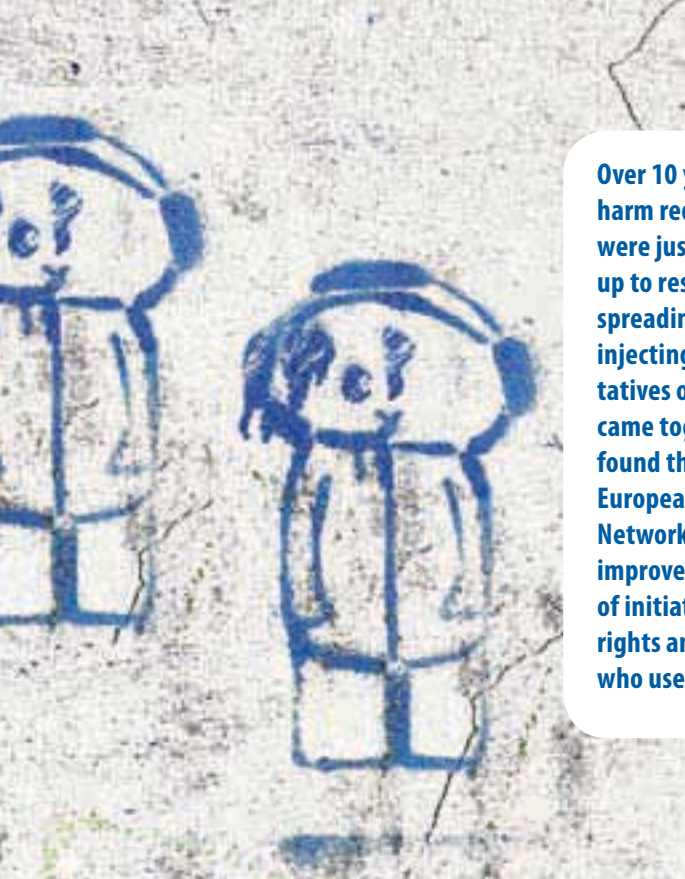
EURASIAN HARM REDUCTION NETWORK

**EHRN**

## The Eurasian Harm Reduction Network (EHRN)

*Interview with Shona Schonning,  
Program Director*





**Over 10 years ago, when many harm reduction programs were just beginning to be set up to respond to the rapidly spreading HIV epidemic among injecting drug users, representatives of various programs came together and decided to found the Central and Eastern European Harm Reduction Network to work toward the improvement and expansion of initiatives supporting the rights and health of people who use drugs.**

Today there are 29 countries represented among the network's members, which number over 300. The network is governed by a democratically elected steering committee that includes representatives of 7 sub-regions plus two representatives of communities of people who use drugs. In 2007, the network's name was changed to "The Eurasian Harm Reduction Network" to more accurately reflect its geographic coverage.

The network, in its various advocacy, information, and technical assistance initiatives, tries to support drug user involvement.

**Shona Schonning**, *Program Director at EHRN's Secretariat, has a long history of supporting community mobilization initiatives mostly among groups of people living with HIV and is a strong believer in the importance of meaningful involvement of people who use drugs.*

**Kaleria:** *How can drug user involvement be improved?*

**Shona:** “We need to do more to enable participation of drug user representatives in decision making mechanisms like Country Coordination Mechanisms, civil society forums on drug policy, boards of directors of harm reduction organizations, in local roundtable discussions etc. It’s important. And it’s not just about having a token drug user in the room. A well-prepared representative can have great impact whether it is on a national committee or a project oversight committee. And even many harm reduction organizations still don’t do enough to involve drug users.”

**Kaleria:** *What about drug user involvement in local harm reduction services?*

**Shona:** “Harm reduction projects need to see drug users not just as clients but partners in an effort to make communities safer and healthier. Some harm reduction projects and services are better than others at this. Involving drug users in project steering committees and listening to drug user feedback about the quality and scope of services offered is important and so is employing drug users. This kind of involvement makes programs more effective and is also empowering for the community. People feel good when they see that they contribute to making their communities healthier. But unfortunately there are still some projects out there that still don’t see it this way and it limits the quality, scope and cov-





erage of their services. Positive change starts at home and harm reductionists should be a model of user empowerment and live up to this most basic feature of our field.

In a lot of programs the rights of outreach workers, many of whom have had some kind of experience with use of illegal drugs, to safety and decent pay seem to be neglected. Obviously when the projects are on a shoestring budget they can't cover everything but I think we need to try to do better. I know a lot of programs for example

that don't provide hepatitis B vaccines to their staff who exchange needles – we need to start advocating among donors and employers to take care of this – it's basic workplace safety and recommended by WHO. I also think we need to try to start allocating money for better salaries for outreach workers. In Russia, Andrei Rylkov started up an outreach worker labor union that was intended to address issues of salary, safety, and continuing education. He was on the right track. Doctors and other health workers get these kinds of benefits. And outreach workers are our frontline – their jobs are important – and we need to make their jobs rewarding and safe.

I also think that employers need to take some responsibility when their



staff members experience relapses or start to experience problematic drug use. I know it is not realistic for a cash-strapped program to be able to afford an elaborate rehab program every time, but if an employee experiencing a problem wants help accessing addiction treatment, I think the employer should try to help. Relapse is a natural part of addiction and for a former drug user working as an outreach worker it can be an occupational safety issue.”

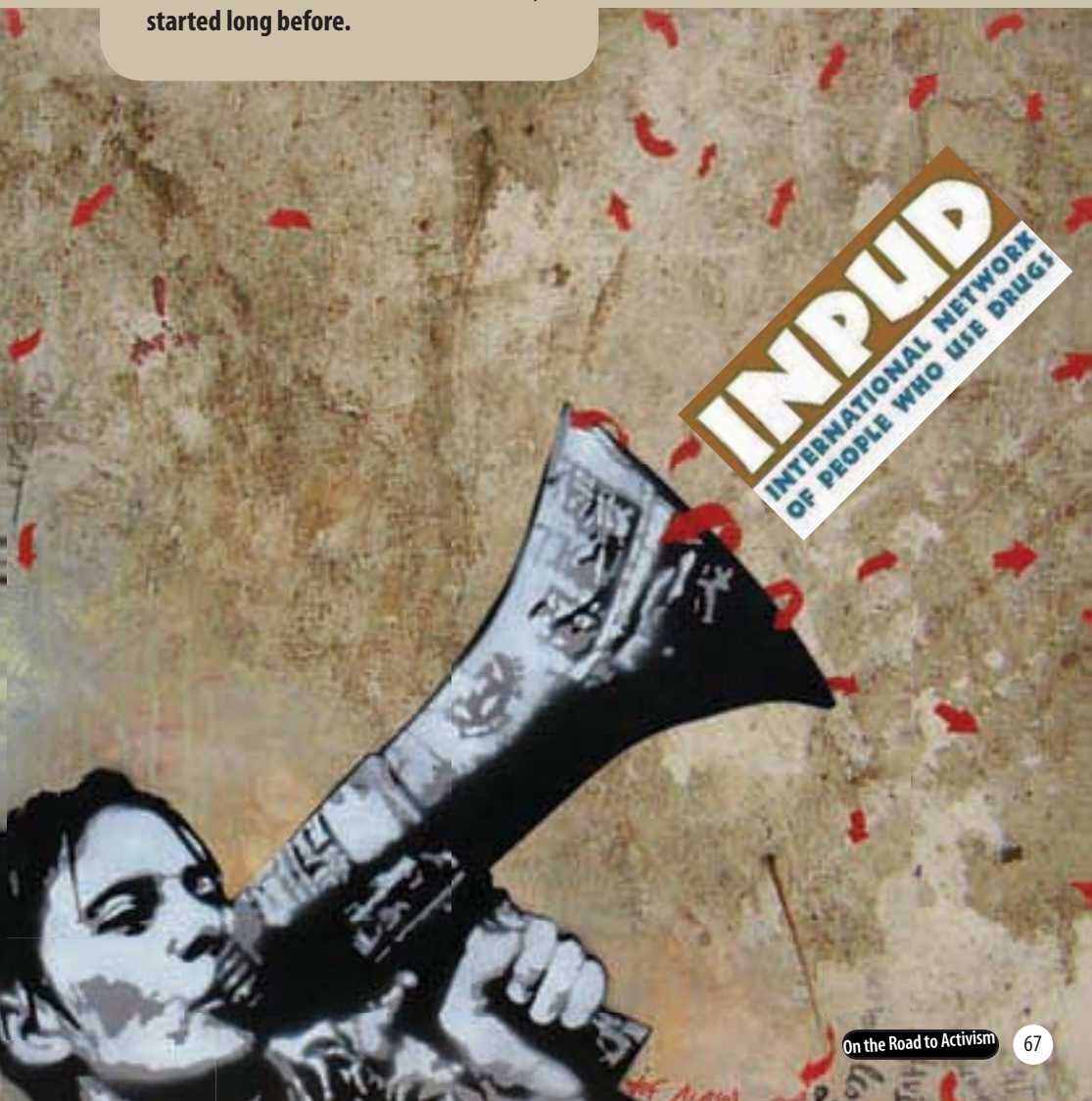
**Kaleria:** *How does EHRN try to involve drug users?*

**Shona:** EHRN supports the involvement of drug users in a number of ways. We have two seats on our Steering Committee reserved for representatives of people who use drugs. When possible, EHRN encourages other harm reduction organizations to involve drug users in their decision making bodies. We work with drug users as members, experts, and consultants. We often try to provide scholarships for drug users to our trainings and other events, and when possible we make arrangements for substitution therapy clients to access required drugs. Cooperation with drug user organizations like INPUD is important. Making publications like this is one of the ways we try to encourage drug user involvement.



# The International Network of People who Use Drugs (INPUD)

The International Network of People who Use Drugs (INPUD) was formally established in 2007, but it had actually started long before.



INPUD emerged as a result of many years of drug user activism in many countries where the drug user community demanded that their perspective should be taken into account in the design and implementation of the national and international response to drug-related problems.

The idea of setting up an international drug user activist network originally came about in 1997, but it was many years later, at the 2005 International Conference on the Reduction of Drug Related Harm (ICRDRH) in Belfast, that the idea once again came into focus as drug user activists from different countries engaged in discussions with members of the International Harm Reduction Association (IHRA) and the OSI International Harm Reduction Development Program (IHRD).

After a year, the 17th ICRDRH in Vancouver, Canada, featured the First International Congress of People Who Use Drugs, giving activists an opportunity to discuss and define the concept and goals of the network. More than 120 people came together to write the Vancouver Declaration, the founding document of the International Network of People Who Use Drugs.

After the Second Users Congress in Warsaw in 2007, INPUD was legally established as an organization with a head office, elected board, one salaried staff member, and a growing membership base. Seed funding from IHRA supported the network's basic needs for the first three years. INPUD has initiated and supported regional sub-networks in order to be more flexible and responsive in providing assistance to its local members.



In August 2007, they established INPUD-Asia, while INPUD-Europe engaged with the European Commission to facilitate the involvement of civil society in the development of drug policies. Forty activists from the United States and Canada attended the first meeting of INPUD-North America, along with their colleagues from Europe, Latin America, and Asia.

Today INPUD is a network of drug user community activists from every continent. They stand for better opportunities and a greater role for the drug user communities and individuals, promote a better understanding of the life experience of people who use drugs, advocate for their rights, and lobby for evidence-based approaches in the design of health services and policies affecting their lives.

*Aleksandr Levin*



## List of organizations of people with drug-using experience and people living with HIV/AIDS in Central and Eastern Europe and former Soviet Union countries:

### Georgia

#### New Vector

##### Tbilisi

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#### Drug Policy Georgia

##### Tbilisi

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#### Tverskaya Alternativa

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### IDU\_Community

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### VERA

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### Timur Islamov Fund

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### Ukraine

#### Association of Substitution Therapy Advocates of Ukraine

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### Chance Club Sumy

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### SPIN Plus NGO

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### Azerbaijan Public Helath Association

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## Key organizations in other countries

### International Network of People who Use Drugs (INPUD)

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### Mainline

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### Svenskabrukarforeningen Stockholm, Sweden

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innovative Drogenselbsthilfe  
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**Stigma  
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