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*Strengthening community-mobilisation on HIV and AIDS
in Central and Eastern Europe*

HIV & AIDS in POLAND

**A non-governmental
overview**

**Fighting HIV as a democratic responsibility:
an overview of the situation in Poland in 2003**

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Lead authors: Arnaud WASSON-SIMON and Olivier DENOUE

Proofreading and Editing: Linda WASSON-SIMON

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*Olivier DENOUE, Wanda GADOMSKA-BOUNAKOFF (interpreter),
Arnaud WASSON-SIMON and Wojciech TOMCZYNSKI*

This report is mostly based upon 2 missions carried out by AIDES representatives to Poland as part of the INTEGRATION Project 2001-2003 (www.integration-project.org). It was fully reviewed by both the NGOs BADZ Z NAMI and AIDES.

(1) Between November 26 and December 3, 2002, Arnaud WASSON-SIMON and Olivier DENOUE from AIDES, with Wanda GADOMSKA-BOUNAKOFF (volunteer French-Polish interpreter), participated in the 9th International Conference of People Living with HIV/AIDS in Family and Society and visited HIV/AIDS NGOs and health care centres in Warsaw and Krakow.

(2) From June 26 to 29, 2003, Arnaud WASSON-SIMON participated in the 7th National Meeting for People Living With HIV/AIDS, organised by the polish NGO BADZ Z NAMI.

These missions formed the opportunity for AIDES to work again with "BADZ Z NAMI", the Polish association of volunteers against AIDS. This Polish NGO, which is fully based upon the mobilisation of people living with HIV, was started in 1995 after its founders participated in a training programme for volunteers set up by AIDES in France.

Overall, the country-missions were designed to see how the NGOs operated in the field: if a lot of information can be shared in international conferences, a lot more can be learned when taking the time to see on site how local NGOs work.

As an organisation founded upon the mobilisation of People Living with HIV and their peers, our main concern at AIDES was to be sure we could hear from PLWHA themselves what they thought of their situation in Poland.

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Executive Summary:

It would not be so hard for Poland to provide optimal care and treatments for all PLWHA who need it.

Compared to both Western and Eastern Europe, Poland can consider itself lucky with regards to HIV/AIDS as the epidemic has remained quite low so far. Even though the government has affirmed quite early its commitment to fight HIV/AIDS, promote prevention and provide treatments, this national commitment remains all too often limited by severe budgetary constraints.

These shortcomings are very dangerous, especially considering how swiftly the situation has changed in nearby Belarus or Ukraine. The cost of providing optimal treatments to all residents of Poland who need it is certainly not out of reach: at most, only 5000 persons currently need HAART. It is also very much within reach to make sure that harm reduction outreach projects are streamlined across Poland to guarantee that all drug users face the minimal risk of being contaminated by HIV or hepatitis C. Harm reduction should of course include the distribution of complete injection kits (not just needles) in order to also prevent the spread of hepatitis C.

The situation of drug users in Poland is in fact quite worrisome: even though 60% of the HIV epidemic in Poland is related to drug users sharing needles, drug users with HIV can find it very hard to have access to decent care. The consensus (among medical practitioners, but also for some NGOs...) is that "HAART are expensive drugs which should not be wasted upon active drug users"... Drug users are therefore strongly invited to "become clean" before they can hope to have access to treatment. This view completely ignores the well-established observation that drug users who take substitution treatment (such as methadone or buprenorphine) tend to have an extremely good adherence to HAART (that is better even than for non-drug users).

At this point, only 900 drug users receive methadone in Poland. There is hope however: at the National Meeting for People with HIV/AIDS, Arkadinz NOVAK, a Catholic priest who is a leading governmental advisor regarding HIV/AIDS, described in a speech on June 27, 2003, how methadone represents a chance for drug users to enrol in HAART.

In the field, most of the NGOs providing direct prevention and support services remain very fragile financially: with the notable exception of MONAR - a NGO managing both harm reduction and abstinence-based centres for drug users - which has been able to secure several relatively stable sources of funding, all other NGOs depend upon short term project-centred funding, which often comes from European or international sources. The notion that public officials should be held publicly accountable for their actions is slowly but surely progressing in Poland. Every year the NGO BADZ Z NAMI organises a national meeting of PLWHA where everyone can talk freely about their experiences with the health care system. These testimonies reveal that there remain severe shortcomings that are most often not mentioned in official reports on AIDS. As the National AIDS Centre is committed to implementing the best possible care for PLWHA in Poland, it should not hesitate to provide core funding to BADZ Z NAMI so that it can develop its role as an independent auditor of users of the health system!

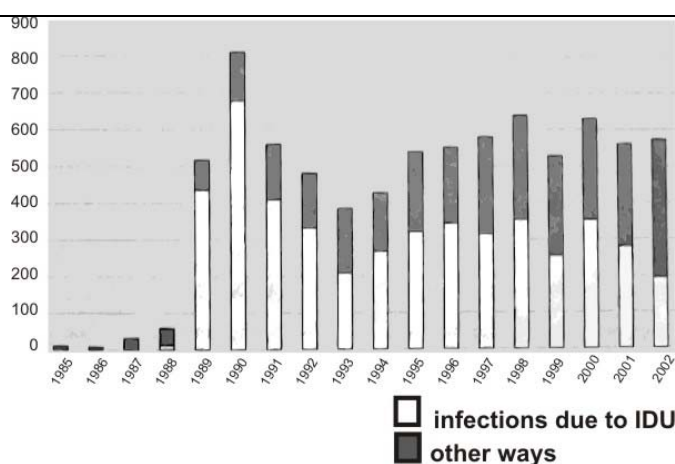
Finally, all actors in the fight against AIDS in Poland are extremely aware of the gravity of the situation in Eastern Europe, and many NGOs and governmental bodies are already implementing projects within Belarus, Ukraine or Russia. Poland can in fact play a key role organising and structuring the EU response to this HIV catastrophe. It could lead for instance, by pledging its equitable contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Fact Sheet: HIV/AIDS in Poland

With about 38 million inhabitants, Poland is the largest of the 10 countries that will join the European Union in 2004. In the 2000 World Health Report, the public health system of Poland was ranked 50th out of 191 countries in terms of “performance” (ranking 5th among the 13 applicant countries). Like most of the countries of Central Europe, the prevalence of HIV/AIDS has remained low. The incidence of new AIDS cases per year has varied between 2,6 and 3,9 per million people between 1994 and 2001. It is much lower than the European Union average, which has varied between 66,8 and 23,3 over the same period (Source EuroHIV). So far in fact, the dynamics of the HIV/AIDS epidemic in Poland seem little affected by the explosion of new cases of HIV faced by its three neighbour countries: Belarus, Ukraine and the Russian Federation (Kaliningrad District).

HIV in POLAND: 1985 – 2002 :

Main ways of infection infections : Intravenous drug use and other ways



This illustration shows that the proportion of HIV transmissions related to the sharing of needles by drug users is decreasing compared to other modes of transmission, such as heterosexual or homosexual unprotected sex. (Graphic produced by the Polish National AIDS Centre in the report: HIV/AIDS, The Polish Policy)

As of late 2002, a total of 7880 HIV infections have been officially registered in Poland, about 60% of which are attributed to the sharing of needles among drug users. Since the beginning of the HIV epidemic in 1985, there have been 1240 AIDS cases and 608 deaths registered (Source National AIDS Centre). It is estimated that the total number of people with HIV in Poland is between 14 000 and 20000.

SOURCES: EuroHIV, UNAIDS and National AIDS Center, POLAND

Presentation of NGOs working in the field of HIV/AIDS:

Five of the main non-governmental organisations working with HIV/AIDS in Poland are:

- **Res Humanae**, a foundation created in 1993 by Father Novak and two close associates who had been working with drug users;



- **MONAR**, a movement begun in 1981 (giving rise to a non-profit organisation in 1989) that works with drug users; MONAR was officially registered in 1981 and has become Poland's leading provider of health services for drug users. It manages both therapeutic communities that intend to help drug users to become abstinent and harm reduction projects. At MONAR-Krakow, we met with Beata SIEROCKA who works on outreach projects, notably targeting sex-workers. In the Warsaw office, we met with Marek ZYGADLO, who manages harm reduction projects for drug users.

In Warsaw, we went with the MONAR team to one of their daily outreach meetings with drug users near the main train station. The backpack contains both clean needles and a container for dirty needles. Regrettably, at this point MONAR cannot afford to distribute more elaborate injection kits (which would include a cup and a hygienic swab, or even condoms).

- **Badz z Nami**, whose creation in 1993 grew out of exchanges with AIDES, upon which it is modelled: a volunteer-based organisation of HIV-positive individuals offering volunteer training, a telephone hotline, etc.

- **Lambda**, an organisation working with gays and lesbians;

- **TADA**, an outreach organisation for sex workers.

These organisations—some of them quite large (MONAR, for example, has 350 paid employees and 250 volunteers)—subsist primarily on public funding, which provides more than two thirds of their budget. Private funding mostly comes from pharmaceutical companies and the Soros Foundation. Financial support from private individuals is virtually nonexistent. (An appeal for donations sent to 10,000 people by Res Humanae—which is in the mainstream of public discourse on HIV/AIDS—netted a total of 10 replies. Only three contained cheques.)

Since much of the public funding is distributed via calls for grants, competition between the organisations for this money is fierce. Criticising the institutions responsible for AIDS funding is, therefore, definitely not advised—unless you're willing to risk your organisation's survival. In any case, none of these organisations take such risks; any problematic political positions or demands are stifled before rising to the level of conscious thought. Only the occasional request (usually regarding a special case) discreetly reaching government ears through well-placed friends is likely to get results.

Their precarious situation is made worse by the fact that government funding does not cover the organisations' administrative costs (rent, telephone, electricity, etc.). As MONAR puts it, "Sometimes we have trouble paying for paper and pens."

The competition for money is a drain on organisation resources since finding funding sources and putting together applications is very time-consuming. In addition, it hurts the relationship between these groups, which need to work together. For example, the registration fee for Res Humanae's Warsaw Conference was €100 for all participants, even for NGOs. If the National AIDS Centre hadn't helped out at the last minute with some of the fees for Badz z Nami, this organisation—the symbol of solidarity with Poland's HIV-positive population—would not have been able to participate.

Both the Catholic Church's influence in the fight against AIDS in Poland and the organisations' lack of visibility limit the number of new volunteers. That most of these groups have chosen not to disown their roots or their principles in order to win over the media and the general population hasn't helped. Their activities involve fieldwork with the most vulnerable, and often least-accepted, members of society: drug users, homosexuals, prostitutes and foreigners (mainly from ex-Soviet bloc countries).

Often based on community action, this type of work does not easily lend itself to bringing in new members. For example, MONAR wanted to recruit a co-ordinator for its new gay and lesbian programme in Krakow from within the community in order to preserve the quality of action. It took a lot of time and energy to find someone who accepted his or her homosexuality and was capable of organising such a prevention project.

The determination to respect a certain ethic while running their programmes, combined with the awareness of their organisational fragility, has had a definite impact on these organisations. In its "Umbrella" programme for sex workers in Krakow, MONAR didn't want to give prostitutes as many condoms as they asked for because it feared the women would become completely dependent on the organisation for their supply. As the programme's co-ordinator explained, "We know that we can disappear from one day to the next."

Faced with these problems (lack of finances, type of claims, lack of recognition, etc.) and the need to circumvent far-too-often unworkable official channels, the organisations resort to personal networking.

Using personal connections in the fight against AIDS

It's a good bet that if Badz z Nami founder and vice president Wojciech J. TOMCZYNSKI hadn't been on friendly terms with the director of the National AIDS Centre, the only organisation representing people with HIV/AIDS in Poland wouldn't have been able to attend the 9th International Conference for PLWHA in Family and Society. Even better, the director in question, Anna MARZEC-BOGUSLAWSKA—understanding the value of an organisation like his in the fight against AIDS—asked Mr. Tomczynski to speak at the closing session, despite the fact that he wasn't on the programme.

Government officials responsible for HIV/AIDS seem to accept a certain disparity between the official discourse—which takes public opinion into account and avoids

offending the Catholic Church on taboo subjects—and a behind-the-scenes support for key actors whose organisations are better able to deal with affected populations and help to stop the spread of the disease.

The NGOs are well aware of this disparity and make great efforts to stay on good terms with various key people in governmental institutions and the medical establishment in order to further their cause. We heard several concrete examples of the need for such relationships:

- There are only 30 doctors prescribing antiretrovirals in Poland, where access to treatment—while effective—remains difficult. Having “connections” with some of these doctors sometimes clears the way for a patient who doesn’t have (or no longer has) access to treatment.

- The director of Res Humanae related an anecdote summing up the importance of personal relationships in Poland: “An HIV-positive person with a broken leg went to the hospital for treatment. As soon as they realised the person was seropositive, the staff sent the person to a different hospital that dealt with HIV/AIDS. The infectious disease service in question, having no expertise with bone fractures, sent the person to yet another service. We ended up using our connections with influential people to resolve the problem. In individual cases, personal connections can often take care of things.”

- Res Humanae’s director also talked about “the need to know highly placed officials in order to get funding more easily.” He may have been alluding to the organisation’s co-founder, Father Novak, who has become the Ministry of Health’s HIV/AIDS advisor.

- MONAR explained the value of maintaining a good relationship with certain members of the police force, in order for its work with drug users and sex workers to keep going. According to Beata SIEROCKA, head of the “Umbrella” programme in Krakow, it happens that “some police officers come to warn us a few days before a raid to expel foreign sex workers.”

- MONAR-Krakow also refers drug users to the few doctors or “ally” organisations that provide truly anonymous and free testing. Activists from MONAR “test” these organisations before sending people there. MONAR also had to wait for a new director of the university infectious disease clinic before it could denounce the disgraceful testing practices of his predecessor, who had violated patients’ anonymity.

- Beata SIEROCKA also told us how her NGO had to use its connections with the National AIDS Centre to pull strings so that an HIV-positive, drug-addicted woman could get her child back after tests showed that the child had not been abused.

- Finally, the following example illustrates the government’s schizophrenic behaviour in the fight against HIV/AIDS: the Krakow regional authorities that fund a large part of the Umbrella programme didn’t want the usual “programme co-funded by



Mateusz LIWSKI,
Director of the NGO
Res Humanae

the regional authority” to appear on the official report. Of course, the programme *is* aimed at sex workers, especially foreign women... the authorities do not want to be seen as being associated in any way with such controversial groups...

The central role of the Catholic Church

It is impossible to understand the current AIDS battle in Poland without taking into account the Catholic Church’s dominant role in society. Since the Church is the most powerful force for profoundly influencing public opinion and behaviour, its involvement in the fight against AIDS sustains at least some collective awareness of what’s at stake with regard to HIV in Poland. Also, clerics who are involved in this area are generally part of the “modernisation” fringe, and will occasionally speak out courageously on the HIV/AIDS problem and HIV/AIDS issues linked to the traditions and mores espoused by most of their colleagues. This work may, in the long run, lead to changes in the Church’s reactionary stance on questions of HIV/AIDS, its very detrimental opposition to condoms and, more generally, on sexuality.

Nevertheless, the clergy and a few AIDS-activist priests are not an effective answer to the burgeoning epidemic knocking at Poland’s doors.

Therefore, we recommend the government to absolutely free itself from religious control and institute an independent, transparent, and relevant anti-AIDS policy as soon as possible. Having taken a clear position, the government wouldn’t need to constantly manoeuvre between its public stance, acceptable to the Church, and its appropriate, if sometimes cloaked, support for activist organisations. Distancing itself from the Church would no doubt entail wholehearted support for the many organisations that have proven their dedication and effectiveness in a difficult environment. Poland’s integration into the European Union, which maybe will tend to moderate the role of the Church, should facilitate this clearer separation.

Building bridges in times of crisis: cross-border solidarity with Belarus, Ukraine and Russia:

All of the Polish actors in the fight against AIDS that we met, both in NGOs and at the governmental level, are extremely aware of the catastrophic situation regarding HIV/AIDS in Poland’s eastern neighbours. In spite of the dramatic historical divisions between Poland and the USSR, in spite of the imminent integration of Poland in the EU which could encourage Poland to ‘just forget about its eastern neighbours’, many Polish NGO activists are already setting up concrete bilateral action plans to strengthen the response against HIV/AIDS in Eastern Europe. At a time when the physical eastern border of Poland has never been so impenetrable (thanks to new anti-immigrant infrared radars and high fences with full time guards that are being heavily subsidised by the European Union...), many in Poland realise they cannot stay still

while Belarus, Ukraine and Russia are facing a wide-scale HIV catastrophe.

Notably, Poland's UNDP office, in link with the Minsk UNDP office, has greatly facilitated links between Polish HIV/AIDS NGOs and their Belarusian colleagues: a first meeting in June 2002 in Minsk was designed to "empower PLWHA NGOs through creating an enabling environment for co-operation with governmental institutions" (UNDP HIV/AIDS Newsletter October 2002). UNDP also facilitates links between Polish and Belarusian doctors, nurses and governmental institutions, to foster the exchange of best practices against AIDS.



"In Belarus, Russia, Ukraine and even Lithuania, having access to HAART is like winning the lottery: the odds are not in your favour".

Eastern European Guests at the Polish National Meeting for People Living with HIV/AIDS.

Together MONAR and the Polish National AIDS Centre are also developing joint projects concerning Eastern Europe.

During the 2003 meeting of People with HIV/AIDS in Posnan, a specific session was dedicated to the situation in neighbouring countries: guests from Ukrainian, Russian, Belarusian and Lithuanian NGOs intervened. In all four countries, the most shocking element is the utter lack of access to antiretroviral treatments: in spite of the exploding epidemic which now affects hundred of thousands, only a handful of citizens in these four countries have access to HAART.

In Ukraine, the situation is expected to improve for the better with regards to access to treatments due in part to the 92 million USD grant it has been able to obtain from the Global Fund to Fight AIDS, Tuberculosis and Malaria (in Round 1). Of course, Ukrainian NGOs want to be sure the Ukrainian plan against AIDS will be implemented as fast as possible, and in a professional rigorous and transparent manner...

Igor AFANASJEV from the Lithuanian Positive Group described how only 25 people at this point were getting HAART (which is controlled by the Lithuanian National AIDS Centre). Mr. Afanasjev has written several public letters to the government asking notably that the criteria for inclusion for HAART be enlarged.

In Russia, as health care is managed at the regional level, there are great differences between for instance, the Moscow District and St. Petersburg, the only two places where some patients receive HAART, and the rest of the country. Activists in the Kaliningrad District of Russia especially feel extremely isolated.

The Belarusian guests said at last that they were very touched by the participation of Ms. Kwasniewska, the Polish president's wife, at the meeting of PLWHA. They said they did not even know who their president's wife was. At this point it remains unthinkable for them that any high-ranking official would pay attention to them.

What concrete steps can Poland take to contribute to the fight against HIV in Eastern Europe?

Civil society in Poland has demonstrated that it is very committed to finding solutions to the HIV catastrophe that is now affecting Poland's neighbours. It is indeed urgent that action to develop prevention, harm reduction and access to care and support be organised on a wider scale: in an alarming report published by the CIA in September 2002, it is estimated that in 2010, from 6 to 11% of the adult population in Russia could be HIV positive. The CIA estimates that this health catastrophe is likely to have a major



Acting against AIDS, literally: this play was presented at the "9th International Conference of People Living with HIV/AIDS in Family and Society" in Warsaw in November 2002

negative impact upon the economic and political stability of Russia.

It is obvious that Poland would also be protecting its own interests by combating the spread of HIV in neighbouring countries. A very significant first step for Poland could simply be to contribute to the funding of the Global Fund to Fight AIDS, Tuberculosis and Malaria. Economists working for the Fund the Fund campaign (www.fundthefund.org) estimate that an equitable contribution for Poland to the Global Fund (ie: a contribution indexed upon Poland's actual capacity to contribute) would represent a total of about 81 million USD between now and 2005.

The 7th National Meeting for People Living with HIV/AIDS

High profile guests attend the 7th National Meeting for People Living with HIV/AIDS (PLWHA) in Poland (June 26-28, 2003 near Poznan, Poland).

Jolanta KWASNIEWSKA, the wife of Alexander KWASNIEWSKA, president of Poland, gave an affectionate speech at the Meeting of People with HIV/AIDS. She especially recalled how proud she is to have been a long-time partner of the fight against AIDS. Several participants took this opportunity to share with her the issues they are facing.

Father Novak, special advisor to the Polish Government regarding HIV/AIDS, has been a long time activist in the fight against AIDS. He notably co-founded Res Humanae, one of the first Polish NGOs dedicated to fighting AIDS.

In his speech, Father Novak confirmed that even though times are difficult in the health department, the budget to fight AIDS has been secured and will be stable. The 1500 persons in Poland who take HAART treatment should not have to worry about continuity.

Further, Father Novak affirmed his support for methadone treatment for drug users as representing a chance for drug users to enrol in HAART. Considering that most AIDS cases in Poland concern drug users, and that most are excluded from HAART because they are considered unable to follow the treatment, Father Novak's announcement is greatly significant.



Jolanta KWASNIEWSKA, the wife of the President of Poland with Wojciech TOMCZYNSKI



This coffer is where a Warsaw hospital keeps its methadone. With only less than 1000 people in total getting methadone... it is a hard-to-reach product indeed!



Ms. Kwasniewska, the president's wife, made a point of attending the 7th National Meeting for People Living with HIV/AIDS, organised by BADZ Z NAMI.

Are there enough anti-AIDS treatments for everyone?

Officially, the Polish health-system is able to provide complete HAART to all Polish citizens who need it. But the truth may be a bit different: According to a Polish activist we met in Warsaw, there may be about 200 people on a waiting list for HAART. A person with HIV who attended the meeting for PLWHA believes that considering that the budget for treatment is very limited, when a new person needs treatment, he or she probably has to wait for a patient on treatment to die... It may also be the case that doctors take into consideration whether there is still funding available or not when prescribing HAART.

At the Meeting for People Living with HIV/AIDS, the participants had the chance to share experiences they have had with the health system:

"I just could not find a dentist who was willing to take care of me. Somehow all the dentists in my town knew I was HIV positive and none would agree to take care of me."

"Some dentists now even require you to fill in a form where you have to declare your HIV status."

"The nurse at the HIV testing centre said she could not use a new pair of gloves for each patient: she only had 2!"

"I paid 100 Zlotis (25 Euros) to have a rapid HIV test in a private practice: I was shocked to see that I had to give them my full name."

"Sometimes we have to wait for months before we can have an appointment with the specialists in Warsaw and then... the appointment gets cancelled at the last minute."

"I was on a waiting list to get Interferon for my hepatitis C virus, but when they found out I was HIV+, they just crossed me off the list. I guess they thought it was pointless to treat someone who is going to die soon..."

"We should make sure there are qualified doctors who are knowledgeable about AIDS across the country and not just in Warsaw: paying for the train every month can be very expensive."

"I am Ukrainian - and I am able to get anti-AIDS treatments because I have a job here. But my work contract ends in one week and I do not know what I will do after that..."



Sharing experiences safely at the Meeting for People Living with HIV/AIDS

THE ROLE OF PEOPLE WITH HIV/AIDS

1) *The true face of the epidemic has not been shown*

Poland is no exception to the rule: the voices of those with HIV/AIDS are rarely heard in public because here, like elsewhere, AIDS is not just another disease. In Poland, particularly, the disease carries too many taboos. Here and there, a few courageous initiatives—like that of Badz z Nami activists photographed with Poland's First Lady, Jolanta KWASNIEWSKA—have put a face on the epidemic. But it's usually children with HIV/AIDS who are offered up to personify the epidemic, despite the fact they are hardly representative of those affected.

In its own way, the media participates in a kind of "disinformation" about the reality of people affected by the epidemic in Poland—primarily drug users. *Le Monde* and RFI, mentioned above, believe that Father Novak best symbolises the Polish AIDS battle—forgetting the many organisations that work directly with the epidemic. Beata SIEROCKA has given up hope of interesting the Polish media in the true face of AIDS, as groups working in the field, like MONAR, see it. The interview she finally gave to a Krakow newspaper was never printed. And here's another example: Polish television recently organised a debate on prostitution, inviting three prostitutes to participate. A brief investigation, motivated by the surprising answers given by these three guests, revealed that the "prostitutes" in question were actually actresses hired especially for the debate... who knows what real prostitutes would have had to say?

These anecdotes demonstrate rather well the difficulty in evoking and showing the reality of the epidemic in Poland. In this way the International Conference in Warsaw put aside the grassroots players and individuals affected by HIV/AIDS. To put up a good show, a "token HIV positive" person was invited, a Swede originally from Poland and a regular of the big international conferences, who gave his consensual, right-thinking speech on the theme "Let's love one another." The odds are that drug users grouped at Warsaw's central railway station or the HIV positive people involved in community action would have had another message to get across.

2) *The role of HIV positive individuals in associations*

All the associations claim the presence of people directly affected by HIV/AIDS among their ranks because it involves the very legitimacy and credibility of these structures.

On the one hand, for an association such as Badz z Nami, the issue seems understood because it was founded for and by those affected by AIDS. So HIV positive individuals are at the heart of a militant action that should be better armed to find answers to the concerns of the epidemic because the virus directly concerns them. Thus Badz z Nami opened a telephone help line, comparable in many ways to the Sida Info Service help line in France, and organises a general assembly every year, gathering together and training more than 100 volunteers. The only problem with this proximity to the epidemic is that the members of the association have never spoken of drug users, and yet this is the major group affected by HIV/AIDS.

On the other hand, the role of HIV positive individuals in the other structures is much harder to grasp. Res Humanae affirms that, following the example of Badz z Nami and the other associations, HIV positive individuals are indeed present in the foundation. But it did not show its concern for the integration of persons affected by AIDS at the Warsaw Conference even though they ought to have been at the heart of the debates.

MONAR, for its part, is more a community association for drug users than an association for the defence of the ill. This is why themes on HIV/AIDS are not a big part of their prevention brochures. However, the association tries to best adapt its responses to the needs expressed in the field. For example, faced with the arrival of many Russian-speaking prostitutes, MONAR is currently preparing publications in Russian.

Despite flaunting the will to integrate HIV positive individuals in the fight against AIDS, their involvement seems very limited, or in any case, not very visible. This discretion, coupled with the relative lifelessness of the associations, engenders numerous deficiencies in the response given to people affected by HIV/AIDS.

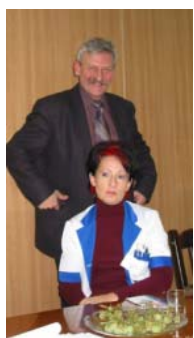
3) Big gaps in the response to the needs of affected people

In Poland, there is no opposition force made up of associations and affected individuals facing the public authorities and the medical profession, which are in charge of dealing with the epidemic.

The effect of this imbalance proves detrimental to HIV positive people:

- For various reasons (morality, observance, finance), "active" drug addicts that have not joined a substitution programme do not have access to ARV treatments. This explains in part the fact that barely 20% of HIV positive people are under ARV treatments. There is a consensus on this choice because even the associations supposedly defending the interests of the ill do not call this option into question. Propositions aiming to make more room in the methadone programme could have mobilised the associations sector in order to broaden access to treatments, for example.

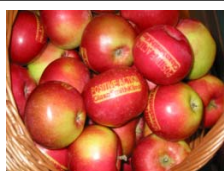
- "Why do you want to listen to the ill or the associations on the question of treatments when it is we, the doctors, who have and master the knowledge of the medications!" Doctor Andrzej HORBAN, Director of the Warsaw regional hospital, doesn't mince words. And it doesn't seem to occur to him that patients, when they are well informed and sufficiently organised so as to speak collectively, have an opinion to give on the constraints of observance and side effects. Once again, the point of view of the ill is non-existent because the associations do not represent it. Must we point out that respect for the ill isn't one of Doctor Horban's strong points? He, who forgetting that we had an interpreter, proposed to his colleague to take us to meet his "junkies"... The hegemony of the "medical views" is obvious before the incapacity of the ill to make themselves heard: the patient does what the doctor orders.



Dr. Horban (one of the leading Polish medical expert on treatments) with colleague.

- Some associations deplore the "submission" of the patient with respect to the doctor. According to Tadeuz Res Humanae, "the ill aren't used to complaining, they are afraid of the medical profession." We would like to act in favour of respecting their rights, but we can't do anything against their will if they do not "wish" to claim these rights."

- Finally, this absence of a positive balance of power between the representatives of the ill and the institutions leads the associations to greatly limit their fields of investigation. For example, it is regrettable that an association like MONAR "is satisfied with" the distribution of clean syringes without taking on the public authorities on the availability of sterile syringe kits (like Stéribox), much more effective in protecting drug-users against infection by hepatitis C virus (as 90% of drug-users are infected by hepatitis C).



"Advertisement Apples"
distributed by the pharmaceutical company GSK at the AIDS Conference: GSK has a major pharmaceutical production plant near Poznan. It benefited from specific tax-exemptions set up by the Polish government to attract investments.

The difficulties encountered by the associations in establishing their role as well as a relatively low prevalence rate contribute to marginalizing and isolating HIV positive individuals. The precariousness in which the associations operate does not allow them to develop innovative prevention and support strategies more in phase with the needs of their users. Furthermore, faced with public institutions and a medical profession that are pre-eminent, they are not yet in a position to impose questions about AIDS patients' rights, access to treatments for all and the different approaches to prevention in the public debate.

There is then a major risk of seeing the associations become limited to the role of a mere "operator" of the public authorities - contenting themselves with responding to the National AIDS Centre's calls for tender, for example, leaving aside their fundamental mission of putting forward claims and taking stands in favour of PLWA's needs and rights.

Again, it is the responsibility of the state to give strong support to the associations that will be the main purveyor of relevant messages and actions likely to respond to the epidemic stakes.

Key Contacts in Poland:

(Country Code for Poland: Dial +48)

NGOs	
<p>1. ASSOCIATION OF VOLUNTEERS AGAINST AIDS „BE WITH US” / BADZ Z NAMI</p> <p>00-355 Warszawa ul. Tamka 37/56 tel/fax 022826 42 47 tel: 022692 84 40/41 e-mail: swwaid@neostrada.pl; swwaid@free.ngo.pl www.http://free.ngo.pl/swwaid</p>	<p>2. POLISH FOUNDATION FOR HUMANITARIAN AID 'RES HUMANA'</p> <p>00-672 Warszawa ul. Piękna 64a tel/fax 022626-86-59 e-mail: resaid@waw.pdi.net</p>
<p>3. MONAR ASSOCIATION</p> <p>00-681 Warszawa ul. Hoża 57 tel: 022621 28 71 fax: 022 622 00 10 e-mail: poradnia.mpnar@wp.pl</p>	<p>4. ASSOCIATION OF VOLONTARIATE FOR THE BENEFIT OF CHILDREN 'LITTLE PRINCE'</p> <p>03-812 Warszawa ul. Kamionkowa 49 m 15 tel: 022810 08 13 e-mail: poczt@mal-y-ksiazek.org www.dzieciwaid.pl</p>
<p>5. LAMBDA WARSZAWA ASSOCIATION</p> <p>00-682 Warszawa ul. Hoża 50/40 tel/fax 022628 52 22 e-mail: lambdawa@lambda.org.pl www.lambda.org.pl</p>	<p>6. ASSOCIATION OF YOUTH & FREE „TOLERSEX”</p> <p>00-987 Warszawa 4 skr.poczt129 tel/fax 022 322 60 72 e-mail: tolersex@tolersex.queer.pl http://www.tolersex.queer.pl</p>
<p>7. ASSOCIATION OF VOLONTEERS „DADU”</p> <p>71-460 Szczecin ul. Broniewskiego 12 tel. 091454-24-50</p>	<p>8. CRACOW ASSOCIATION FOR AID TO ADDICTS</p> <p>31-063 Kraków ul. Św. Katarzyny 3 tel: 012 430 61 35 fax: 012 430 59 64 e-mail: monar_kr@monar.krakow.pl</p>
<p>9. FOUNDATION OF SOCIAL EDUCATION</p> <p>02-555 Warszawa Al. Niepodległości 151/16 tel: 022 646 48 86 e-mail: megama@poczta.onet.pl</p>	<p>10. ASSOCIATION „SOCIAL AID”</p> <p>01-199 Warszawa ul. Leszno 17 tel: 022 632 07 25</p>
<p>11. SOCIAL COMMITTEE FOR AIDS</p> <p>00-681 Warszawa ul. Hoża 72 tel: 022 812 58 11 e-mail: VIDAS@wp.pl</p>	<p>12. ASSOCIATION FOR PREVENTION OF HIV/AIDS AND OTHER STDs – TADA</p> <p>ul. Małkowskiego 9/2 70-305 Szczecin tel: 091 433 44 58 e-mail: tada@free.ngo.pl www.tada.pl</p>
<p>13. ASSOCIATION „PLUS-MINUS”</p> <p>50-225 Wrocław ul. Reymonta 8 tel.: 071 329 08 96</p>	<p>14. ASSOCIATION CATHOLIC MOVEMENT AGAINST DRUGS KARAN</p> <p>03-750 Warszawa ul. Grodzka 65 tel: 022 679 02 33 e-mail: karan@karan.pl www.karan.pl</p>

Governmental Organisations	
<p>NATIONAL AIDS CENTER</p> <p>02-829 Warszawa ul.Samsonowska 1 tel: 022 331 77 77 fax: 022331 77 76 e-mail: aids@aims.gov.pl www.aims.gov.pl</p>	<p>NATIONAL BUREAU FOR PREVENTION OF DRUG ADDICTION</p> <p>02-776 Warszawa ul.Dereniowa 52/54 tel: 022641 15 01 fax:022641 15 65 e-mail: bdsnark@medianet.pl www.medianet.pl/~bdsnark</p>
<p>POLISH SCIENTIFIC ASSOCIATION FOR AIDS</p> <p>71-455 Szczecin ul.Arkońska 4 tel/fax: 091 454 14 59 e-mail: annabk@inet.com.pl</p>	<p>UNITED NATIONS DEVELOPMENT PROGRAM (UNDP)</p> <p>AL.Niepodleglosci 186 02-086 Warszawa tel; 022 825 92 45 e-mail: registry.pl@undp.org www.undp.org.pl</p>



Warsaw, November 28, 2002

Major changes within very little time: the Polish capital with many new constructions ongoing reflects the frantic pace of the reforms taking place in Poland.

The fight against AIDS in Poland, an interview following the first country-mission (December 2002)

Intevieu of Arnaud WASSON-SIMON (by Agnes Leonard for www.aides.org - 2002)

What is the prevalence of AIDS in Poland?

It is estimated that there are up to 20 000 HIV positive people at most in Poland. So the prevalence of AIDS is relatively low in this country. And yet Poland is close to countries that are very affected. Indeed, and fortunately, the players in the fight against AIDS in Poland are wholly conscious that their country is very close to Ukraine, Russia, Belarus and the Baltic States which, in less than 4 years, have become the countries the most affected by AIDS in Europe (essentially because of the dramatic rise in infections among drug users).

What can you tell us about the activists of the associations?

I'd especially like to speak to you about the association Badz Z Nami, founded in 1993 with strong support from AIDES (at the initiative of Daniel DEFERT), which is still as militant and active today as it has always been. According to Wojciech TOMCZYNSKI, co-founder of the association, HIV positive people in Poland have to dare to defy society's taboos and break out of their isolation and solitude. He intervened during the closing of the Warsaw Conference against AIDS and questioned the audience on the place of HIV positive individuals in Polish society (while at the same time deploring their absence at this conference!).

And what about religion in all of this? What is the context?

The Polish Catholic Church, as one might expect, is very present in the debates on HIV/AIDS. On the one hand, we can only salute the commitment of numerous priests who dare to contradict the Pope by encouraging the use of condoms. On the other hand, we can only deplore the dominance of prejudice against gays, the exclusion of prostitutes, and the difficulties in speaking openly of sexual practices.

Is anything being done for drug users?

As we have seen, the use of drugs is in large part responsible for the dramatic rise in infections in the bordering countries, and the use of intravenous drugs represents without a doubt the major mode of transmission of the disease in Poland. And yet, Poland is not moving much on this viewpoint. We know for example, that there are clearly too few places in substitution programmes for drug users in Poland (only 1000 people are on methadone). Rather than continue to systematically exclude active drug users from anti-AIDS treatments, Poland should urgently integrate access to substitution as an essential element in the fight against AIDS. We know perfectly well that individuals on substitution have excellent observance to anti-AIDS treatments.

MONAR, which was originally an association for the rehabilitation and promotion of abstinence among drug users, was intelligent enough to integrate harm reduction into its practices very early on (exchange of syringes and taking care of those on methadone).

In conclusion

Immigrants without proper working or identity papers in Poland remain systematically excluded from medical care in this country. But in 2004, with Poland becoming part of the European Union, the eastern border of the country will be closed for the first time in generations. It is estimated that thousands of Ukrainians will try to immigrate to Poland while it's still possible. It is imperative to guarantee them access to health care, without which we run the risk of seeing public health catastrophes develop on the fringes of the official health care systems. Isn't it up to the European Union to guarantee that the right to health is a fundamental right for all of its residents? Shouldn't it contribute to the financing of this care, so that this right is guaranteed even in the poorest countries of the EU?

The priorities of BADZ Z NAMI for 2004 and beyond

As the leading Polish NGO founded upon the mobilisation of People Living with HIV and their advocates, Badz z Nami maintains a wide scope of activities: after the entry of Poland into the European Union, we anticipate being able to both develop our relations with our partners in Western Europe, and also, because of our geographic situation and our history, to work more in partnership with our eastern colleagues who are now facing a catastrophic increase in HIV incidence. Overall, our working plan includes the following:

I/ Managing the Support and Information Centre for PLWHA's, created to provide versatile psychological support as well as integrate the society of PLWHA and their families/partners through:

- Active job-search and professional consulting
- Consultation and information centre
- Education group
- Women's support group
- Rehabilitation and sport activities
- Therapeutic and psychological support group
- Support group for the families and partners of PLWHA's
- National AIDS/Hepatitis B and C Hotline available 24 hours a day, 7 days a week
- Volunteer help for AIDS patients at home and in the hospitals
- Annual National Meetings of PLWHA
- "To be and to stay together" – programme dedicated to couples living with HIV/AIDS
- Magazine "Live Positive" issued quarterly
- "A day of fulfilled dreams"- programme dedicated to women living with HIV/AIDS
- Acceptance Salon – monthly social gatherings for those tested HIV+
- "Positive Friday" – monthly social gatherings for men who have sex with men

II. Close collaboration with international NGO's:

- | | |
|--|-----------|
| 1. AIDES | France |
| 2. SidaInfoService | France |
| 3. Noaks Ark | Sweden |
| 4. Pozitivnoye Dvizenye | Belarus |
| 5. Agihas | Latvia |
| 6. Pozitivnaya Grupa | Lithuania |
| 7. Espo | Estonia |
| 8. All Ukrainian Network of PWA | Ukraine |
| 9. Other NGO's from Moldova, Kaliningrad, Czech Republic and Hungary | |

III. Collaboration with large international NGOs, organisations and networks such as: UNAIDS, UNDP, EUROCASO, EATG and Open Society Institute

IV. Collaboration with Polish HIV/AIDS NGOs

Contact :

**BADZ Z NAMI / ASSOCIATION OF VOLUNTEERS
AGAINST AIDS „BE WITH US”**

00-355 Warszawa

ul.Tamka 37/56

tel/fax 022826 42 47

tel: 022692 84 40/41

e-mail: swwaims@neotrada.pl; swwaims@free.ngo.pl

[www.http://free.ngo.pl/swwaims](http://free.ngo.pl/swwaims)