

Interim Project Grant Report Form

Basic Information

OSI Grant ID#: 20034905
 Grant project title: Availability of medicines is a right not a privilege
 Organization name: Biedriba Apvieniba HIV.LV (Society "Asociation HIV.LV")
 Contact person: Aleksandrs Molokovskis
 Total grant awarded: 24,749.00, 1-st installment 17,324.30
 Grant start and end date (month/day/year): 02.01.2012 – 01.31.2013
 Report due date: 07.10.2012
 Report submission date: 07.13.2012

Narrative Report (5 pages or less)

I. Project purpose

In 1-2 sentences, please restate the aims of the project.

To conduct advocacy activities for increasing access to medicines for the treatment of HIV and hepatitis C in Latvia. To study and analyze the problems of access to essential medicines, and to identify tools for improving access. To improve the advocacy skills of community representatives and patient advocates.

II. Activity summary

Please describe the activities you have undertaken to date for this project. Compare your planned work with the work and timeline described in your original proposal. Include the goal of each activity, partners you collaborated with, concrete outcomes, and particular challenges and obstacles you faced. You are welcome to submit any materials (reports, brochures, etc.) you have so far produced in connection with this project.

The most important planned activities	Scheduled time	Implementation time	Implementation level and clarifications
<u>Objective 1:</u> To study and analyze the problems of access to essential medicines, realistic opportunities for its expansion and to identify tools for improving access			
Legal research by lawyer. There were topics studied: parallel import of medicines; distribution of unregistered medicines in Latvia; medicines pricing principles; amendments to the Pharmacy Act;	Since February till April, 2012	Finalized at May 24, 2012 delayed due to a lawyer change	Research made by lawyer (Ronalds Rozkalns, Attorney at Law at Individual Legal Practice, LinkedIn profile at http://lv.linkedin.com/pub/ronalds-rozkalns/14/41/27b?_mSplash=1) and the original is published at http://www.apvienibahiv.lv/docs/729/Projekti_2012/Petijum

Baltic Partnership Agreement.			s_RozkalnsR.pdf 18 conclusions made. Research is translated into Russian.
Compile a report on the problems and needs of the community of patients living with HCV (to study problems and needs of people living with HCV and co-infection HIV/HCV)	Since February till April, 2012	Finalized at July 5, 2012 delayed because there was problem to find persons for a work with patients having HCV mono-infection	Research made by 3 patients advocates (Aleksandrs Samarins – outreach worker for drug users; Laila Berzina – general practitioner in Bolderaja doctorate; Agita Seja – social worker in NGO-s DIA+LOGS, AGIHAS, Association HIV.LV, psychologist, researcher) 1) Methodology of research (made by Ieva Pranka, profile at http://www.yasni.de/ieva+pranka/person+information) The originals of methodology documents are published: Questionnaires for patients (are translated into Russian) at http://www.apvienibahiv.lv/docs/729/Projekti_2012/anketa_pacientiem_FOSI.doc ; http://www.apvienibahiv.lv/docs/729/Projekti_2012/FOSI_anketa_ielu_darbsLV.doc ; http://petijums.lv/limesurvey/index.php?sid=26429 The Guidelines for interviewing doctors – regional infectologists (only in Latvian) at http://www.apvienibahiv.lv/docs/729/Projekti_2012/Vadlinijas_ekspertu_interv.doc The Guidelines for focus groups (are translated into Russian) at http://www.apvienibahiv.lv/docs/729/Projekti_2012/Fokusgrupas_pacientiem.doc 2) Questioned 98 patients having HCV. Summary published (now translating into Russian) at http://www.apvienibahiv.lv/docs/729/Projekti_2012/Anketu_apkopojumsFOSI.pdf 3) 3 focus groups performed (5 patients with HIV/HCV; 5 patients with HCV due to drug use; 5 patients with HCV due to medical reasons). Summary published (now translating into Russian) at http://www.apvienibahiv.lv/docs/729/Projekti_2012/Fokusgrupas_FOSI_2012.pdf 4) Research, “problem tree” and “objectives tree” analysis published (now translating into Russian) at

			http://www.apvienibahiv.lv/docs/729/Projekti_2012/Petijums_pacientiLAT.pdf 5) Report on the problems and needs of the community of patients living with HCV published (now translating into Russian) at http://www.apvienibahiv.lv/docs/729/Projekti_2012/Zinjojums_VHC2012.pdf 6 conclusions made.
Develop a list of recommendations to improve access to essential medicines and bring them to the attention of decision makers	April, 2012	Not implemented because of delay with researches	Planned at the week July 16 – 20, 2012
Round table with decision makers	May, 2012	1-st in May 22, 2012	Discussion – round table in closest cooperation with Hepatitis Society held. There participated representatives from Parliament, Ministry of Health, National Health Service. http://www.hepatits.lv/lv/nozares-eksperti-norada-uz-tuliteju-nepieciensamibu-iesaistit-valsts-augstakas-amatpersonas-c-hepatita-izplatibas-ierobezosanai-latvijam-nepieciensams-tikai-miljons-latu The round table with decision makers on topics of this FOSI project will be hold at October or November, 2012
Monitor the situation with the formation of lists of reimbursable medicines, their pricing under the compensation system and its financing, the number of patients on treatment	permanently	permanently	602 unique patients received HCV treatment and 641 HIV treatment by 1-st May, 2012 (respectively 774 and 1063 patients during the whole year 2011). Prices of medicines did not change. Society's "Association HIV.LV" representative is an associated member of the Pharmacy Council (under the MoH) since February 23, 2012, but a member of the Pharmacy Council's working group on improvement of compensation system and patients' access to medicines since July 9, 2012. We note that the State Secretary Council announced at July 5, 2012 changes in Cabinet Regulations (http://www.mk.gov.lv/doc/2005/VMNot_020712_ZIKS.692.doc)

			<p>see article 1.7) that the price of reimbursable medicines forward must be not the 3-rd lowest in the whole EU, but the 3-rd lowest comparing to Czech, Dane, Romania, Slovakia and Hungary.</p> <p>But the situation with compensatory system in Latvia becomes very threatening because Pharmaceutical companies refused to pay 4 million LVL to cover the deficit of budget for reimbursable medicines in 2012 – as they did so in 2011,- and therefore the deficit forecast by the MoH will be 8 million LVL; and the MoH now examine such options as for example to reduce compensation 75% level back to 50% - this should affect all HCV patients, and 100% level to 95% - this should affect all HIV patients (http://nra.lv/latvija/75570-zalu-budzetam-draud-pamatigs-deficits.htm)</p>
<p>Reporting to the Parliamentary Sub-Committee on Health Affairs</p>	<p>June, 2012</p>	<p>May 8 and May 23, 2012</p>	<p>The 2011 FOSI project results were presented at sitting on May 8, 2012 (http://titania.saeima.lv/livs/saeimasnotikumi.nsf/0/48BBD63DE2C29EF7C22579F70025DCCB?OpenDocument).</p> <p>The discussion was about reimbursement level for HCV medicines, HCV treatment in prison system, Register of HCV patient, Hcv treatment in Lithuania and Estonia.</p> <p>There were discussed also some recommendation of the project. The MoH said that because the Minister of Health is changed after new Parliament elections, also priorities are changed. Therefore this is not the topic to establish the Register of HCV patients. More about implementation of recommendations-2011 see below. The next Sub-Committee sitting on HCV issues is planned ... 2 years later, the Chairman of the Sub-Committee Vitalijs Orlovs said.</p> <p>On May 23 there were sitting to make proposals to change the Law on VAT, because of The</p>

		<p>Government plan to reduce VAT for 1% since July 1, 2012. We proposed to reduce VAT for reimbursable medicines from 12% to 5%, but VAT for non-reimbursable medicines from 12% to 10%. (Society SUSTENTO proposed to reduce VAT for all medicines from 12% to 11%.) The Sub-Committee accepted our both proposals. But the Parliament did not accept any proposals to reduce VAT for medicines and it still is 12%, however the common VAT reduced from 22% to 21%. This is noted in the legal research by lawyer.</p>
<p><u>Objective 2:</u> To conduct advocacy activities for increasing access to medicines for the treatment of HIV and hepatitis C through direct interaction with the State institutions</p>		
<p><i>Tracking implementation of recommendations of the "Report on the hepatitis C virus (HCV) and its treatment situation in Latvia" 2011:</i></p> <p>1a) The MoH should maintain the 75% level of State- compensated hepatitis C medications for in- patients as of January 1, 2012; - done</p> <p>1b) simultaneously considering a higher compensatory level of up to 90% as of July 1, 2012.- Asked by the MoH, National Health service has calculated additional financing needed – 860 thousand LVL. After this there is written a letter to MoH to increase the level up to 90%. But Hepatitis Society requested 100%. No answer received from MoH.</p> <p>2) and 3) about changes in Cabinet Regulations 899 – not implemented yet. This is a topic to work in Working group of the Pharmacy Council (under MoH authority) on improvement of compensation system and patients' access to medicines, established at July 9, 2012 (mentioned above).</p> <p>4) The Latvian Infectology Centre (LIC) and the Health Economics Centre should create hepatitis C patients' register and start its operation as from January 1, 2012. - Such was a written order made to LIC. But Health Economics Centre was eliminated since November 1, 2011; the new Minister came since October 25, 2011, and she has not among her priorities infectious diseases; LIC is eliminated since April 1, 2012.</p> <p>5) The Health Economics Centre should elaborate and confirm a medical technology of increased treatment adherence of all patient groups, and start implementing it as of July 1, 2012. - The query was discussed by Coordinative Commission on limiting the spread of HIV, TB and STD at 10.26.2011 (http://www.apvienibahiv.lv/docs/729/Komisiju_protokoli/VEC_prezent_lidzestibaHIV.zip), 06.06.2012 (there is not minutes of sitting yet), and at 06.28.2012 (http://www.apvienibahiv.lv/docs/729/2012_dazadi/NVO_Priekslikumi_pasakumiem_lidzestiba.doc)</p> <p>6) The Health Economics Centre should include the innovative HCV protease inhibitors in the list „C” of State- compensated medications as of March 1 – It is not possible this time, because MSD will begin its' “early access program” of boceprevir, and the boceprevir must not be sold in the market, if early access program starts. Telaprevir still is not registered in Latvia.</p>		

- 7) The LIC should elaborate and register new and substantial Clinical Guidelines for diagnostics and etiotropic treatment of hepatitis C; - **This is in process by the Association of Infectologists (NGO), but not LIC (eliminated since April 1, 2012)**
- 8) The LIC should provide prisons with HIV and hepatitis C antibody express- tests; - **Not implemented. LIC is eliminated since 04.01.2012, but HIV prevention makes now the new structure of MoH – The Centre for Disease Prevention and Control (<http://www.spkc.gov.lv/informacija-svesvaloda/>)**
- 9) NGOs together with the State institutions should start creating a complex programme of social accompaniment of HIV and/ or hepatitis C patients;- **it is in process, and the meeting on this issue will take place at 07.23.2012. under “Nothern Dimension” authority and organizing by the Centre for Disease Prevention and Control.**
- 10) The MoH should include into the Consultative Pharmaceutical Council an NGO representative who would directly protect the interests of HIV and hepatitis C infected persons as of January 1, 2012. - **done, since February 23, 2012 (mentioned above).**
- 11) **Unfortunately, GFATM issue really is not is not actual for Latvia because of changes in pilicies of the Global Fund.**
- 12) MH, MJ and MF should reach an agreement on integration of penitentiary medicine into the public healthcare system, and implement the integration as from January 1, 2013. - **Fully implemented. The MoH pays for laboratory examinations since January 1, 2012; imprisoned persons has access to reimbursable medicines and prison doctors have the right to prescribe them since February 1, 2012; imprisoned persons may have their own family doctor (general practitioner) out of prison since March 1, 2012; methadone maintenance and suboxone program are available in prisons for those received opiod substitution therapy before imprisoned since April 1, 2012.**
- 13) **Our organization implements an educational project in prisons "Education as a tool for HIV prevention" (http://www.apvienibahiv.lv/docs/729/Projekti_2012/LOI_HIV_LV_US_Emb.doc), there are printed 2 brochures – “Managing side effects” in Latvian (http://www.apvienibahiv.lv/docs/729/Projekti_2012/Blakusparadibas_2012.pdf), and “Adherence” in Latvian and Russian (http://www.apvienibahiv.lv/docs/729/Projekti_2012/Lidzestiba_LAT_RUS.pdf)**
- 14) **In process with partners NGO-s: Hepatitis Society, DIA+LOGS, AGIHAS**

To monitor the situation with the budget of reimbursable by the State medicines, filing proposals of the National Health Service	permanently	permanently	“Association HIV.LV” representative is an associated member of the Pharmacy Council (under the MoH) since February 23, 2012 - sittings of the Council meeting are held every month-, but a member of the Pharmacy Council's working group on improvement of compensation system and patients' access to medicines since July 9, 2012 – this group works permanently.
Expertise of normative acts and their projects, and writing expert letters	permanently	permanently	There are examined 6 legislation initiatives and normative acts on topics: changes in pricing of parallel imported medicines, the project of new guidelines to treat HIV, changes in order of health care of HIV patients since September 1, 2012 and

			January 1, 2013, changes at Cabinet Regulations 803 and 899. Examinations made by lawyer.
Participation in commissions and councils under authority of the MoH, proposing agenda	permanently	permanently	In the year 2012 – every month. In addition there is signed Agreement on cooperation with Welfare Ministry and our organization at May 10, 2012 to work together on issues related to families of those living with HIV (HIV+ one or both parents, or a child). The first step we agreed is to support from welfare budget milk substitutes if a mother has HIV

Publications, press releases, public actions

- 1) Press releases – 3 – on the FOSI 2011 project results, on the Candle Light Memorial day (there was public action in Riga, photo gallery see at <http://apvienibahiv.lv/pasakumu-fotogalerija>), on the HIV action months at July. The last is named “Hepatitis C treatment costs per month more than human life” (In Latvian <http://apvienibahiv.lv/aktualitates/c-hepatita-arstesana-maksa-menesi-vairak-neka-cilveka-dzive>, <http://www.medicine.lv/raksti/c-hepatita-arstesana-maksa-menesi-vairak-neka-cilveka-dzive>, in Russian <http://www.apvienibahiv.lv/novosti-na-russkom/lechenie-gepatita-s-v-mesjac-stoit-bolshe-chem-chelovecheskaja-zhizn>, in Ukrainian http://faqhepatitis.blogspot.com/2012/07/blog-post_06.html)
- 2) In cooperation with Hepatitis Society we are collecting 10,000 sign-ons to the Parliament to change the level of reimbursement of medicines to treat Hepatitis C to 100%. Collecting of sign-ons takes place at <http://manabalss.lv/par-dzivi-bez-c-hepatita/show?mode=all&type=top> Only residents of Latvia having Latvian ID-code may sign on the petition by authorization through person's internet bank account. The system accounts first name, last name and ID-code of the signer, and there is possible to sign on the petition only one time per person. Therefore this process is very representative, and by the Law The Parliament after receiving 10,000 sign-ons must make decision in 3 months. Up to July 12 there are collected 1,050 sign-ons. Active banners are put on our website's right directory in LAT and RUS chapters.
- 3) On the July 27 Association HIV.LV itself will hold 4 pickets in the same time 12.00-12.30 in front of MSD, MoH, National Health Service and the Centre for Disease Prevention and Control, grinding a liver in mincing machine (unfortunately the owner of the building were is the office of Roche did not agreed with this action). Activists will show printed at typography posters with slogans from the press release mentioned above in Latvian, share information materials, but picket heads will submit claims to these institutions. All these institutions are informed about the planned event.
- 4) There are published at our web-site www.apvienibahiv.lv and at Twitter account https://twitter.com/Hiv_Lv a lot of informations/news on Hepatitis C issues during the project time up to reporting day: in Latvian- 25 informations, in Russian- 22, in English- 1. There were 2 publications on project issues in friendly newspapers in Latvian, 1 in Russian.

Objective 3: To improve the advocacy skills of community representatives and patient advocates

Training on advocacy for members of communities of people living with hepatitis C	June 2012	Not implemented	Will be hold at September, 2012
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and co-infection HIV/HCV			
<p>To prepare for active self-advocacy activities at least one of a representative community of patients with HCV and one with co-infection HIV/HCV</p>			<p>There was a need to change a plan of the project, because of resignation “to work for money from Soros” showed by Hepatitis society. Therefore we founded new NGO “Resurrection” (registered at the State Register of NGOs on June 12, 2012 , see Register data at https://www.lursoft.lv/uznemuma-pamatdati/resurrection). This NGO leads by former drug users, one of them is a member of our Society, and main goals, as written in their statute are: “Help and support for persons dependent on psycho-active substances and other destructive behaviors; training and advice for people with destructive behavior, as well as their relatives and family members; seminars, conferences and other events; to manage and organize activities that will promote hepatitis treatment access in line with the target group.” We supported them with writing the Statutes and registration process, and paid for them the State fee for registration of NGO. We shall work closely with this new organization and teach them. They also will take an active participation in our pickets at July 27</p>
<p><i>Other activities are in normal process, but with a little delay. It is not dangerous delay, because the project was planned to 10 months, but the agreement with FOSI is to 12 months.</i></p>			

III. Future work, changes, and challenges

Please describe your planned work for the remainder of this project. If your work-plan differs from the plan you described in your proposal, please describe any changes you have made and why. If you do not anticipate meeting the goals outlined in your initial proposal, please outline why this, what your revised goals are, and how you will meet them.

Please see the table above – there are named also future works. All activities described at project proposal will be implemented. We do not foresee essential changes in planned activities. The only one problematic thing is constructive cooperation with Hepatitis Society because of their resignation to go along with organization sponsored by the Soros Foundation. We also wrote about this in our 2011 project report.

Financial Report

Please note how much of your grant amount has already been spent, and describe how these funds were used. Compare your spending with the budget and timeline you submitted with the proposal, and discuss any significant differences. Include any funds you received from other sources to support this project. A sample template is provided, please modify it as necessary.

The detailed Budget Report is provided separately.

Expenses from the 1-st installment were planned to 7 project months, till August, 2012.

The lawyer and accountant are changed starting the project, because Tatjana Jefimova resigned from her positions at our organization since February 1, 2012. The new lawyer is Ronalds Rozkalns, Attorney at Law, but the new accountant of the organization is Kristine Bobkova.

There was a problem with “patient advocate” for patients with HCV mono-infection. We planned to pay for this position to representative from Hepatitis Society Olita Mengote, but she categorically refused to be paid by Soros Foundation. Therefore we paid 3 months for 2 people: Aleksandrs Samarins – outreach worker for drug users, and Laila Berzina – general practitioner in Bolderaja doctorate (Riga). Now we are looking for person, who can continue this work. We are studying a number of options.

There also are problem with media-advocate (mass media expert) Inga Paparde. She was paid from the project only for work she really has done, and these were only 2 months paid. This time we have agreement to July with new person – Olga Lvovska (she also has a practise at EHRN). Also in this case we are studying a number of options.

Because of we have seen how well the printed word impacts to the officials – our printed FOSI Report 2011,- it is possible (may be) that after implementation of the main activities of the project 2012 (in October – November, 2012) we shall ask for restructuring of existing budget with a goal to publish the project materials in a printed book in Latvian and in Russian. But it is very hard to foresee this time how many money we can save.