

UKRAINE

**FUCK
CORRUPTION**

 PATIENTS OF
UKRAINE

Corruption in health **kills**
1607* **Ukrainians** every day

*Average number of Ukrainians who die each day of AIDS, tuberculosis, cancer (tumors), circulatory diseases, diseases of the respiratory system, digestive diseases according to the State Statistics Service of Ukraine for 2012–2013. <http://uiph.kiev.ua>



**Olga
Stefanyshyna,**

Executive Director,
CF "Patients of Ukraine"

"I do not trust the politicians in power. I do not believe in the positions: President and Ministers. I believe only in people who have already made two successful attempts to change the history of this country in recent decade. I believe in patients — individuals whose lives depend on medicine — who will drastically and permanently change the health care system in Ukraine. I believe this will happen very soon and each retired person, each pregnant woman, businessman, and politician will be receiving medical services of equal quality. And the government will provide 100% health coverage to those who can't afford to pay for it."

“We don’t need health care reforms on LCD screens during round-table meetings and conferences. Reforms are needed in every doctor’s office of the most remote hospital, ward, and clinic!”



**Dmytro
Sherembey,**

Head of the Board,
CF “Patients of Ukraine”

Report of the CF “Patients of Ukraine” January 2014 – June 2015

About us
7

Health care reform in Ukraine
8

Governmental procurement of medicines and vaccines
10

The national health budget
12

Assistance to patients
14

Accessibility and affordability of HCV treatment
16

Our members
18

Media about our activity
20

Financial report
21

Partners
22

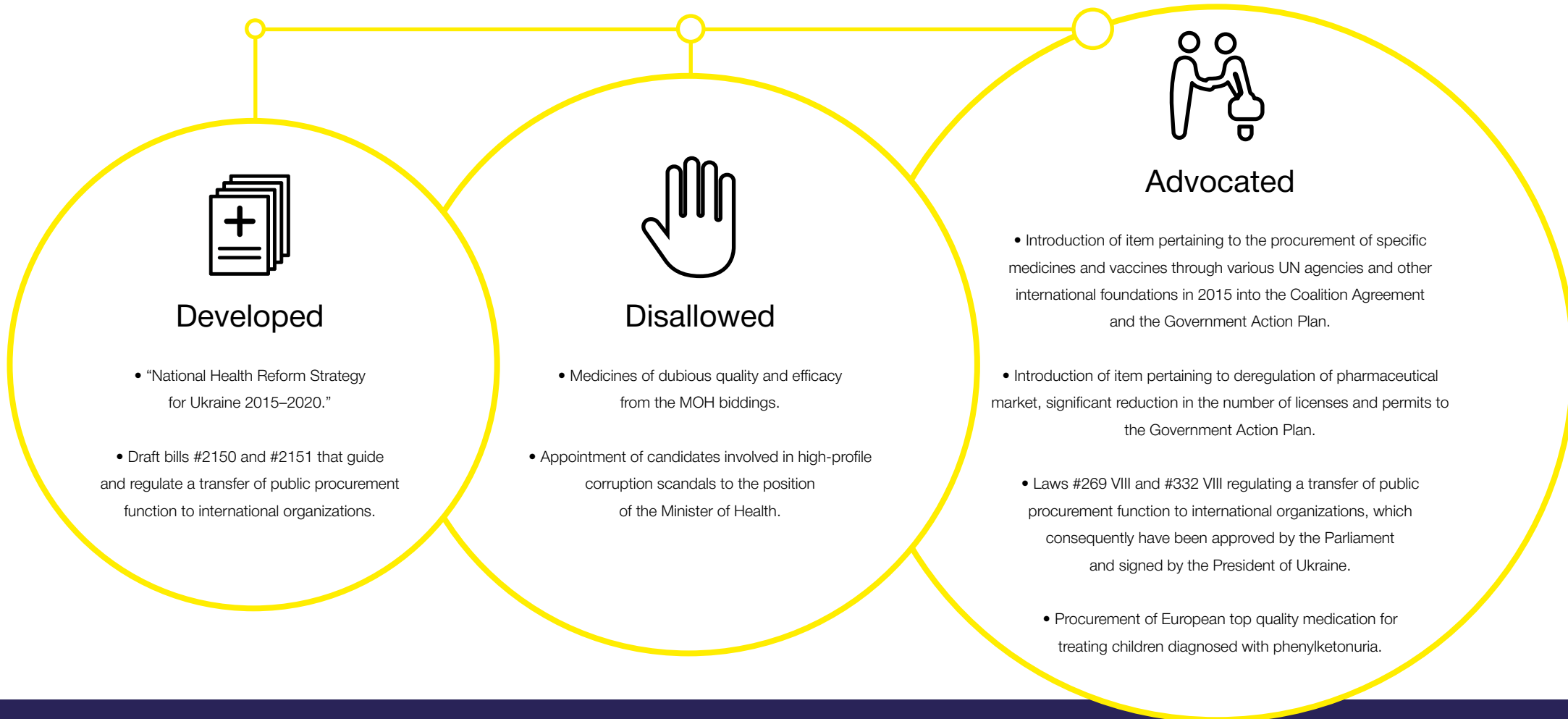
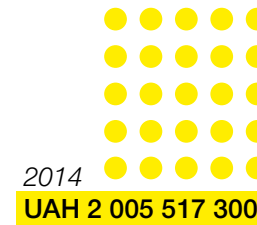
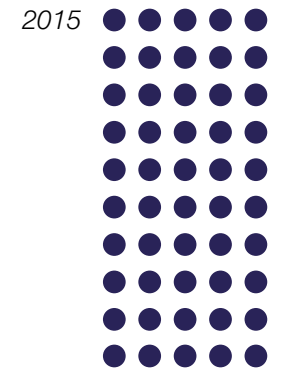


Charitable Foundation "Patients of Ukraine"
Our mission: Treatment available for all!



MOH BUDGET
FOR HEALTH CARE
INCREASED BY
UAH 2 093 340 400

UAH 4 098 857 700



About us



CF “Patients of Ukraine” is comprised of 30 patients-activists having various diseases.

They represent over 120 non-governmental organizations that work for more than 60 thousand people all over Ukraine.

On December 11, 2014, **12 new members** representing various severe diseases, such as hemophilia, phenylketonuria, cystic fibrosis, pediatric and adult cancers, juvenile rheumatoid arthritis and others, have joined the organization during the annual General Meeting of the Charitable Organization “Patients of Ukraine”.

The Board serves as a governing authority of the CF “Patients of Ukraine” and is comprised of patients and activists with an extensive experience in patient rights advocacy.

We advocate patient rights to quality care in the four areas:

- Advocacy of state guarantees for treatment.
- Monitoring of government spending on medications.
- Mobilization of powerful patient movement in Ukraine.
- Health care reform in Ukraine.

“Patients of Ukraine” is the best available remedy to save the ailing Ukrainian health care system. The treatment is complicated but efficient. Thanks to such organizations as “Patients of Ukraine” Ukrainian patients finally got the chance to shift from the category of patients into the category of healthy people.”

Olga Rudneva,
Executive Director, Olena Pinchuk Foundation “ANTI-AIDS”



Health care reform in Ukraine

Prior to the events of winter 2013–2014, the CF “Patients of Ukraine” worked occasionally. We were making attempts to “treat” Ukrainian health care system gradually and symptomatically. However, the Euromaidan opened a window of opportunity for the social lift and created an actual slot to build a new health care system in Ukraine!

Infection criteria

Corruption

Inefficient outdated
system

Critically low levels of trust
towards health providers

Skyrocketing prices for
“free of charge” health
care services

Route to recovery:

CF “Patients of Ukraine” jointly with the Ministry of Health, international and national experts, with participation of the World Bank, WHO Country Office in Ukraine and with the support of the International Renaissance Foundation developed the “**National Health Reform Strategy for Ukraine 2015–2020**”.

Chronology of events:

- **July 24, 2014** — Strategic Advisory Group on healthcare reform in Ukraine (Health SAG) was approved by the MOH of Ukraine. 12 experts were selected to participate in the Strategy development: 7 national and 5 international (Estonia, Croatia, Great Britain, Georgia, and Spain). **The group was comprised of:** Coordination Council, Expert Group and Secretariat. Coordination Council included representatives of the following entities: MOH, Ukrainian Medical Association, **CF “Patients of Ukraine”**, World Bank, WHO, International Renaissance Foundation.
- **December 2, 2014** — one of the Health SAG members, Oleksandr Kvitashvili was appointed as a Minister of Health of Ukraine.
- **December 3, 2015** — a draft of the “National Health Reform Strategy for Ukraine 2015–2020” was published.
- **December 2014 – February 2015** — public discussions of the draft Strategy were held in Kyiv and 4 other regions (Dnipropetrovsk, Vinnytsia, Lviv, Kharkiv). The draft was approved by the Minister of Health Oleksandr Kvitashvili.
- **January 16, 2015** — the draft Strategy was presented to the Parliamentary Health Care Committee.
- **November – December 2014** — introduction of basic interventions outlined in the draft Strategy to the Coalition Agreement and the Program of the Cabinet of Ministers of Ukraine, namely: transfer of public procurement function from the Ministry of Health to international organizations; consolidated three-tier system network of hospitals, deregulation of the pharmaceutical market.





“National Health Reform Strategy for Ukraine 2015–2020” has been developed at the initiative of the CF “Patients of Ukraine”.

“The first time I met the “Patients of Ukraine” they immediately had my sympathy. They looked like a ruffled bunch of guys and girls, prancing around in their colorful, “fuck corruption” T-shirt. Over time, I came to really appreciate their commitment and drive for reforms. I am glad you are there, “Patients of Ukraine”! Keep up with your good work for a better future for your country.”

Paolo Carlo Belli,
Sector Leader for the Human Development Program
in Europe and Central Asia, World Bank





Government procurements of medicines and vaccines

OBJECTIVE

Ensure transparency of the tendering process

Challenge	Activities	Results
<ul style="list-style-type: none"> Medication prices doubled due to the national currency devaluation. 	<ul style="list-style-type: none"> Round-table with pharmaceutical companies was held to negotiate cost reduction options. 	<ul style="list-style-type: none"> Memorandum signed — government procurement prices for medications will remain at the level of 2013.
<ul style="list-style-type: none"> June 2014 — bidding failed to be announced. 	<ul style="list-style-type: none"> Meeting with the Vice Prime-Minister of Ukraine. The challenge was voiced at the National Council on TB and HIV/AIDS. Media pressure on the responsible MOH officials. 	<ul style="list-style-type: none"> Tenders announced.
<ul style="list-style-type: none"> Certain medications were overpriced by 300% at public tenders. 	<ul style="list-style-type: none"> Thematic news-conference. Patients' video requesting pharmaceutical manufacturers to bring the cost down to the level of 2013. Trilateral negotiations: MOH — patients — pharmaceuticals. 	<ul style="list-style-type: none"> Prices were reduced to the level of 2013.
<ul style="list-style-type: none"> September 2014 — 80% of the tenders failed. 	<ul style="list-style-type: none"> Opened petition of the patient community to the Ministry of Health to immediately conduct tenders. A walkout titled "Shoes" was held in front of the Cabinet of Ministers of Ukraine: patients and parents of the ill children brought children's shoes to be displayed in front of the Cabinet of Ministers of Ukraine along with the sad statistic. It reminds of those Ukrainians who died without receiving a government-funded treatment. The shoes symbolize the Cabinet of Ministers of Ukraine as an operation room that decides the destiny of tens of thousands of children and adults with disabling conditions. Campaign "Countdown". Fliers and big banner displayed near the Cabinet of Ministers served as a morning reminder to officials of expiring deadlines. Posters and banners "countdown" in social media. 	<ul style="list-style-type: none"> Resolution of the Prime Minister of Ukraine: all the tenders for medical procurements should be held prior to October 21, 2014.
<ul style="list-style-type: none"> October 21, 2014 — 75% of tenders were not conducted. 	<ul style="list-style-type: none"> "Black Tuesday" — a surge of mass protests of patients overwhelmed 17 cities of Ukraine. 	<ul style="list-style-type: none"> December 31, 2014 — the MOH procured required drugs by spending 84% of the budgetary funding allocated to the Ministry under the treatment programs in 2014.
<ul style="list-style-type: none"> Disrupted procurement of medicines and vaccines in 2014. 	<ul style="list-style-type: none"> Initiative to develop the package of draft bills #2150 and #2151, envisioning the implementation of a new government procurement mechanism for medicines and vaccines through international organizations, in particular UN Agencies, IDA (the Netherlands), Crown Agents (Great Britain), Partnership for Supply Chain Management (PFSCM) (USA), Global Drug Facility (GDF) (Switzerland). 	<ul style="list-style-type: none"> Laws #269 VIII and #332 VIII were approved by the Parliament and signed by the President of Ukraine. In the next four years, medications for Ukrainian patients may be procured by 6 international non-profit organizations enabling to: <ul style="list-style-type: none"> - Eliminate corruption in the MOH procurement. - Save about 40% of public funds. - Timely provide patients with essential quality drugs and children — with vaccines.



Laws #269 VIII and #332 VIII were approved by the Parliament and signed by the President of Ukraine.

"Patients of Ukraine" is passionate in its defense of the health rights of all people in need of good medical care. Through its efforts, it gives a voice to people who would otherwise be silent. Ukraine is privileged to have such an organization in the country."

Charles Lerman,
Director of the Health and Social Transition Programmes Unit, USAID Mission for Ukraine



The national health budget

OBJECTIVE 1

Advocacy of state guarantees for treatment in 2014

Challenge

The plan is to cut financing of national treatment programs by **30%**.

N.B. The 2014 national budget envisioned expenditures in the amount of UAH 2 005 517 300, which (based on estimates of the Ministry of Health) amounted to 29% of patients' needs.

Activities

- The national campaign **"Excises save lives!"** — a proposal to the Parliament to raise the excise tax on tobacco and alcohol and spend a portion of the proceeds on the procurement of the essential medicines.
- **Flash-mob** (March 26, 2014) — over 100 activists and patients laid down on the square in front of the Parliament to illustrate how lives of many Ukrainians will be lost, should MPs ignore this bill. In doing so they will effectively be "trampling" on those lives.
- **Petition** to the acting President of Ukraine, Verkhovna Rada Chairman O. Turchynov, Prime Minister of Ukraine Arseniy Yatsenyuk was signed by more than 30 patient organizations seeking to approve changes to the State Budget of Ukraine and redistribute revenues from the excise taxes by redirecting it for treatment of seriously ill patients and to abolish a 7% tax levied on the supply of drugs.
- Round-table titled **"Emergency exit out of the medical crisis in Ukraine"** with a participation of the Minister of Health, MPs, patients and representatives of various Ministries and departments.
- **"Laying protest"** in front of the Ministry of Finance. Demanding: reallocation of an excessive funding for the procurement of essential medicines.

Results

- Parliament passed legislation to raise excise taxes on tobacco and alcohol. However, this funding was directed not only towards health care and drugs but also to offset the budget deficit on all counts.
- With the efforts of the CF "Patients of Ukraine", the Ministry of Health budget allocated for treatment of children with cystic fibrosis in 2014 was increased by UAH **4 million**.

OBJECTIVE 2

Advocacy of state guarantees for treatment in 2015

Challenge

Pre-crisis situation with financing of drug procurement for 2015: the draft budget sticks to previous year indicators. More than a half of patients within State programs could remain without medications.

Activities

- **A walkout titled "It is easier to kill than to cure"** (December 23, 2014). Demanding: revision of the budget with an aim to budget a UAH 6.8 billion for the treatment of patients with mortal diseases.
- **Participation of the CF "Patients of Ukraine" in the meetings of the Parliamentary Committees on Health Care and Budgeting issues (December 24, 2014).**

Results

- Parliamentary Health Care Committee recommended the government to increase the MOH spending on drugs to UAH 6.8 billion.
- Due to the efforts of the CF "Patients of Ukraine", partners and people's deputies the 2015 MOH budget for treatment was approved in the amount of UAH 4 billion, which exceeds the one adopted in 2014 by UAH 2 billion.



Advocacy efforts of the CF “Patients of Ukraine” helped to increase the MOH budget for treatment by:

- UAH 4 million in 2014
- UAH 2 billion in 2015.

“Patients of Ukraine” is a great example of the grass root civil society organization that is driving forward the health system reform in Ukraine. With hard work and determination they changed the legal environment in Ukraine to allow international organizations to procure medicines that are funded by the state. With their strong motivation and hard work they are enabling the changes that are so needed in the health system in Ukraine.”

Dr. Dorit Nizan Kaluski,
Head of Country Office in Ukraine, World Health Organization



Assistance to patients

On March 25, 2014, over 40 patient and civic organizations, associations and groups signed the Memorandum on Cooperation.

OBJECTIVE

combine efforts to fundamentally and comprehensively support the initiatives aimed to improve access to treatment for Ukrainians

Charitable Organization “Association of parents of children with phenylketonuria “Generation”

Challenge	Activities	Results
<ul style="list-style-type: none"> Russian drug of dubious quality “Tetrafen” was not suitable for the majority of children with phenylketonuria and caused terrible side effects and disability. This drug has been procured for 12 years at a skyrocketing price. 	<ul style="list-style-type: none"> Broad advocacy and high profile media campaign with the technical support of the CF “Patients of Ukraine”. 	<ul style="list-style-type: none"> The Ministry of Health expanded the list of drugs and procured European high quality drug “PAM-1” for the children with phenylketonuria.

Public Organization “Association of patients with pulmonary hypertension in Ukraine”

Challenge	Activities	Results
<ul style="list-style-type: none"> The Government of Ukraine is permanently ignoring the problems of patients with pulmonary hypertension. Funding allocated to support the government-funded medication programs is not available. <p>N.B. Patients with pulmonary hypertension can live up to 3 years in case no treatment is provided.</p>	<ul style="list-style-type: none"> A walkout titled “Life inside a balloon — 3 minutes without a breath” was held in front of the Cabinet of Ministers of Ukraine with the technical support provided by the CF “Patients of Ukraine”, including the flash-mob: patients put on plastic bags on their heads demonstrating inability of human being to breath without air, thus symbolizing patients with pulmonary hypertension who can’t breathe without medications. Demanding from the government: allocation of funding for the state program to procure drugs and provide adequate treatment to patients with pulmonary hypertension. 	<ul style="list-style-type: none"> Public attention has been drawn to this acute problem. Joint efforts gave momentum to proceed with decisive activities in the fight for the right of access to treatment for patients with orphan diseases.

National Cancer Institute

Challenge

Igor Schepotin, an odious director of the National Cancer Institute, has been spearheading the key government cancer agency for 7 years, he also has been involved in multiple corruption scandals. Each of the 18 inspections revealed egregious violations, millions of hryvnias had been overpaid during the procurements of medicines and the purchase of unnecessary equipment.

Activities

- **Media and advocacy support provided to health care providers-activists** by the CF “Patients of Ukraine” and NGO “Anticorruption Action Center” to dismiss the director of the Institute and to draw attention of the law enforcement agency to the instances of corruption in the health facility.

Results

- Scandalous leader was dismissed. The Ministry of Health conducted an open and transparent competition to fill the vacant position with the participation of NGOs. Olena Kolesnik was elected as a new leader, winning 472 of 688 votes from employees of the Cancer Institute.

Patients living with HIV/AIDS

Challenge

It was reported that in June of 2015, about 30 000 HIV/AIDS patients could be left without medications due to corruption.

Cause: the last year’s Resolution of the Ministry of Health and the Cabinet of Ministers of Ukraine #117 allowing drug suppliers to receive a 100% advance payment and supply drugs within the period of 180 days. The drugs were supposed to be supplied by the company “Vector Pharma” by the end of 2014; at the beginning of June 2015 drugs had not yet been supplied.

Activities

- **All-Ukrainian protest action titled “Cemetery instead of drugs” initiated by the CF “Patients of Ukraine” and AUCO “All-Ukrainian Network of PLWH”** (May 27, 2015). The key message: a possible disruption in the supply of antiretroviral therapy may result in a full-blown AIDS epidemic. In Kiev, activists arranged a symbolic cemetery on the slope in front of the Cabinet of Ministers of Ukraine. Social activists, representatives of patient organizations and patients living with HIV/AIDS sought to address the Prime Minister of Ukraine and the Government to immediately influence the critical situation.

Results

- Attention of the Cabinet of Ministers of Ukraine has been drawn towards the issue in question. As a result, the company “Vector Pharma” (renamed as “Fiolis”) provided an official letter to the Ministry of Health of Ukraine and state-owned enterprise “Ukrvaccine” stating its readiness to supply the drugs and to readjust drug prices. Under the condition, budgetary savings may amount to half a million of UAH.

“We all once were or will be a patient. Although, the word patient originates from the word “patient” — “Patients of Ukraine” have lost this silent Ukrainian limitless patience and don’t want to tolerate the carelessness of the government, corruption and lies in the society. I wish all of us – the future or past patients to embrace the brilliant initiative and together build a new system, not only the health system, but also a new country, in which everyone will find an interesting work and the ability to self-realization, professional and timely health assistance and social protection!”

Bogomolets Olga Vadymivna,
civic activist, Honored Doctor of Ukraine, MD, Deputy of Ukraine, Head of the
Parliamentary Committee on Public Health, Advisor to the President of Ukraine



Accessibility and affordability of HCV treatment

Ukraine is among the regions with the highest prevalence of hepatitis B and C. Nearly 8% of Ukrainian population is infected with viral hepatitis. Hepatitis C is the most prevalent epidemic in Ukraine. The major danger: a person can contract the virus in the hospital during blood related procedures, at the dental office and even at a nail beauty shop.

Challenge	Activities	Results
<ul style="list-style-type: none">• A high-quality and innovative treatment of hepatitis C is not available to Ukrainians.	<ul style="list-style-type: none">• A protest action initiated by the patients during the XX International AIDS Conference against the skyrocketing cost of the innovative drug for the treatment of hepatitis C.• Negotiations with the manufacturer of the innovative drug produced for treatment of HCV in the meeting at the Consultative Council for community in Eastern Europe and Central Asia (Eastern and Central CAB).• Trilateral negotiations between the CF “Patients of Ukraine”, the Ministry of Health and the manufacturer of the innovative HCV drug.	<ul style="list-style-type: none">• A possibility of the MOH receiving a new drug “Sofosbuvir” at a special price for the government procurement was discussed. For the first time in Ukraine, it became possible to get the most modern treatment of hepatitis C.
<ul style="list-style-type: none">• Ukrainian market is filled with drugs of dubious quality that could cause harm to a patient.	<ul style="list-style-type: none">• The campaign aimed to curb public procurement of dubious quality HCV drug “Alphapeg”, produced by the “Valartin Pharma”. The pharmaceutical company filed a lawsuit against a number of activists, including Dmytro Sherembey, Head of the Board of the CF “Patients of Ukraine”.• Dmytro Sherembey was acquitted by the court and all the charges pressed against him by the pharmaceutical company were dismissed.• Support provided by the international community: a letter to the Prime Minister of Ukraine Arseniy Yatsenyuk sent by the International Organization Treatment Action Group (TAG) expressing deep concern about the situation with the drug “Alphapeg” produced by LLC “Valartin Pharma”.	<ul style="list-style-type: none">• The drug “Alphapeg” is prohibited by the Ministry of Health of Ukraine Order #914. LLC “Valartin Pharma” was not involved in the bidding process.



The drug of dubious quality and efficacy “Alphapeg” was disallowed from the tender announced by the Ministry of Health of Ukraine.

“I observed “Patients of Ukraine” starting from a small grass-roots organization to a powerful national leader towards real change for Ukrainian patients. Their commitment brought a lot of positive movements in the area of HIV/AIDS and other diseases. And I’m sure, there are many more to come.”

Jacek Tyshko,
UNAIDS Country Coordinator in Ukraine



Our members

"Trainings of "Patients of Ukraine" helped me to become an active and contributing member of the MOH working group on procurement. As a result, we managed to expand the range of products and monitor the quality of drugs for children with autism, epilepsy, and hyperactivity disorder."

Yevgeniya Panichevska,
Head of the CF "Parents Association
for Autistic Children"

"Patients of Ukraine" is a talented and bold team with a sincere heart; they have done exceedingly more for Ukrainian patients as opposed to some of the officials who had been in power for decades. Thanks to the professional work of "Patients" and active advocacy of the rights, many Ukrainians are alive now and receive a life-saving treatment. Thanks!"

Larysa Rybchenko,
Director of the Foundation supporting children with
autism syndrome "Child of the future"

"Collaborating with the team of the CF "Patients of Ukraine" is like an on-going source of inspiration in search of impossible goals and tools of how to achieve them; a complete support enables small patient communities to get an actual opportunity to defend their rights. Thanks!"

Mariya Aylen,
Director of the CF "Open Palms"

"Patients of Ukraine" bring inspiration. Whenever you feel discouraged and want to quit, you begin to recall the titanic day-to-day work of the "Patients", their dedication, courage, and determination. Then you realize that you have no right to let these people down and your strength and faith return to you and you believe that your goal is achievable!"

Nina Astaforova-Yatsenko,
representative of the CF "Children
with hemophilia"

“CF “Patients of Ukraine” — a spearhead of all patient organizations in Ukraine! This tip is made of a charismatic leader and beautiful girls!”

Ivan Zelenskyy,
Director of the CF “A Drop of Blood”

“Patients of Ukraine” regularly support the patient community of individuals with a genetic disorder — phenylketonuria, in defending the rights to the adequate treatment of patients with diagnosis in question. On behalf of all our members, we would like to thank those who are not indifferent to the problems of other patients!”

Natalia Tymoshchuk,
President of the CO “Generation”

“Routine daily activities of “Patients of Ukraine” are very important for our organization. We deal with adult cancers and face with challenges that are not alien to other diseases. Therefore, interaction with other organizations and authorities is fundamental to success in tackling the challenges.”

Tatiana Leman,
Head of the Board of the
CF “Ukrainian Cancer Federation”

“Patients of Ukraine” — an aspen stake in the chest of corrupted Monster living in the bureaucratic jungles of the Ministry of Health of Ukraine. It is inevitable and final!”

Oleg Martynyuk,
Head of Ternopil regional NGO patients with Viral
Hepatitis C “Spark of Hope”

“Contribution made by the team of the CF “Patients of Ukraine” in the Ukrainian health care system over the course of several years has been already felt by the patients of Ukraine. Their important initiatives to introduce systematic changes in the procurement of medicines, to ensure transparency of national tendering process are often resisted by the MOH officials instead of being adequately supported. Such reform initiatives should have had the Ministry and other government entities as partners. I wish the “Patients of Ukraine” to never give up and always remember those who they work for!”

Hanna Gopko,
People’s Deputy of Ukraine



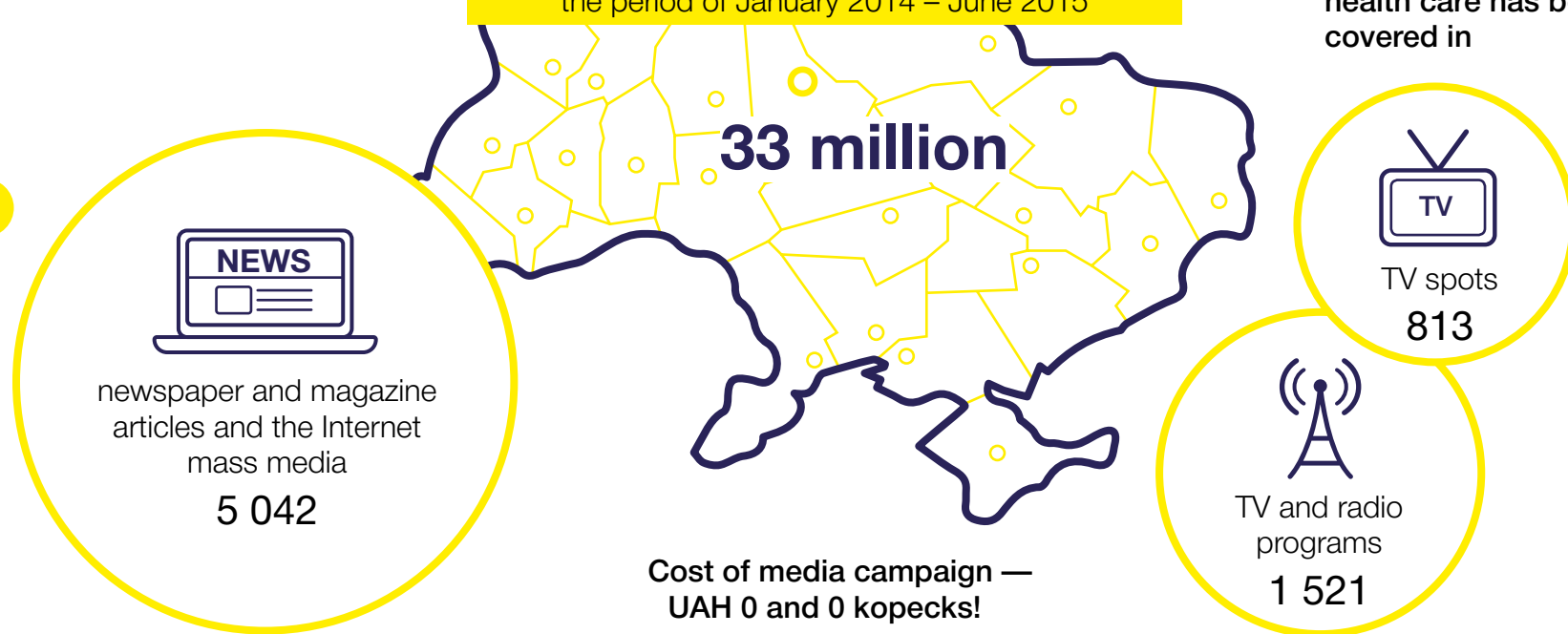
Media about our activity

Media support is one of the key tools to eliminate corruption in health care!

Our activities have been covered in

Covered audience that learned of the procurement related challenges through the mass media during the period of January 2014 – June 2015

Our fight for quality and accessibility of health care has been covered in



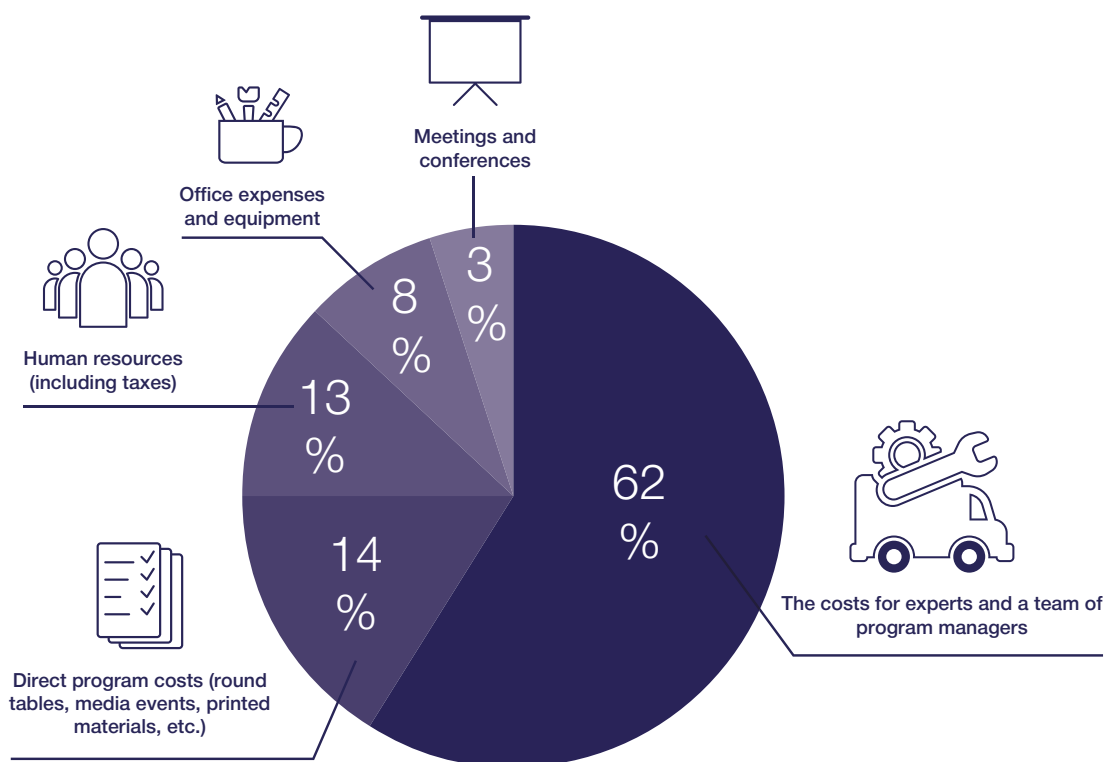
Friends, thank you for fighting along our lines for the life of every Ukrainian patient!

Best regards, CF "Patients of Ukraine!"

Financial report of the CF “Patients of Ukraine” for January 2014 – June 2015



Within the 2014–2015 the CF “Patients of Ukraine” received funding to the tune of UAH 7 384 683.99 for the implementation of 14 projects. As of June 2015, UAH 4 592 265.37 has been spent and accounted for and UAH 2 792 418.62 is in the process of projects implementation.



Donors of the CF “Patients of Ukraine”



“I’ve been so impressed by the activism of the “Patients of Ukraine”, a group that demands and gets results. They remind me of the early ACT UP years in the U.S., when we forced an entire country to respond to its AIDS crisis. Patient advocacy is more crucial than ever in fighting epidemics, and Ukraine needs activism like this, more than ever.”

Peter Staley,
an American HIV/AIDS, LGBT rights activist



Our partners

Who we partner with



Who we are





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