

Health Care Crisis and Grassroots Social Initiative in Post-Communist Russia

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Abstract: This paper analyzes the development of civil society in Russia in response to the fledging post-Soviet health care crisis. The paper focuses on volunteer social work, specifically on grassroots initiatives to help families of children diagnosed with cancer to overcome the everyday psychological, legal and financial difficulties associated with treatment, and to lobby the government to go forward with health care reform.

In recent years, Russian civil society has become significantly stronger and more actively engaged in public debates on social as well as political issues. This trend suggests that in contrast to the "old" civil society, currently positioning itself as a force opposed to the existing competitive authoritarian structure, this "new" civil society has a greater chance of introducing positive change from below.

1. Introduction

The collapse of communism generated much interest in the concept of civil society, regarded as one of the preconditions for the successful consolidation of democracies across the post-Soviet space. As many scholars noted the development of civil society institutions such as sport clubs, media organizations, academia, political parties and non-governmental organizations helped promote democratic norms and values such as tolerance and compromise, thus strengthening democracy.¹ Civil society was seen as an alternative force limiting the overarching power of the state and thus preventing the state from drifting toward authoritarianism. Some scholars pointed out that during democratization, civil society not only helped restrain the government, but educated the state authorities about democracy and rule of law.²

It is no wonder then, that the development of civil society in Russia became the subject of close scrutiny. Opinions varied, with some observers emphasizing the weakness and underdevelopment of Russia's civil society as a result of the Soviet legacy and attitudes held over from the Communist period.³ Others held a more optimistic view, arguing that the development of civil society in Russia had its ups and downs. Indeed, independent social groups and movements, which mushroomed in the late 80s and early 90s, were later replaced with formal NGOs supported by Western aid. Reliance on foreign funding offered these NGOs an opportunity to become important political actors. At the same time, foreign aid contributed to the growing detachment of Western-funded NGOs operating in Russia from local constituencies.⁴ This undermined public support for the third sector, thus slowing

¹ For a detailed discussion of the importance of civil society during democratization, refer to Marcia A. Weigle, "On the road to the civic forum: State and civil society from Yeltsin to Putin," *Demokratizatsiya* (Vol. 10, Nr. 2, Spring 2002), pp. 117-146. And Brian D. Taylor, "Law enforcement and Civil Society in Russia," *Europe-Asia Studies* (Vol. 58, No. 2, March 2006), pp. 193 – 213.

² Marcia Weigle and Brian D. Taylor argue that Russian civil society activists did not see themselves as being in a permanent opposition to the state. Rather, the Russian civil society sector adhered to a 'strong state – strong society' model, whereas the institutionalization of state power was seen as a prerequisite for civil society development, while a strong civil society was considered vital for ensuring the state's democratic orientation. See Brian D. Taylor, "Law enforcement and Civil Society in Russia," *Europe-Asia Studies* (Vol. 58, No. 2, March 2006), pp. 193 – 213. And Marcia A. Weigle, "On the road to the civic forum: State and civil society from Yeltsin to Putin," *Demokratizatsiya* (Vol. 10, Nr. 2, Spring 2002), pp. 117-146.

³ See, for example, Marc Morje Howard, "Postcommunist civil society in comparative perspective," *Demokratizatsiya* (Vol. 10, Nr. 3, Summer 2002), pp. 285-305.

⁴ See, for example, Jo Crotty, "Managing civil society: democratization and the environmental movement in a Russian region," *Communist and Post-Communist Studies* (Vol. 36, Nr. 4, 2003), pp. 489–508.

the process of developing civil society. Many Russians viewed these Western-looking NGOs with great skepticism, accusing them of ignorance and corruption.

This trend played into the hands of Russian President Vladimir Putin, who used it as an opportunity to weaken and gain control of Russia's civil society sector. With the passage of the 2006 Law on NGOs, the development of Russian civil society has faced significant challenges, particularly Western-funded international and Russian NGOs.⁵ The majority of outside observers and civil society participants agreed that the new law drastically limited the ability of NGOs to function as independent organizations. In light of these developments, people began to speak of a hostile environment for NGOs in Russia and a significant regression in democratization.⁶

However, some civil society actors who defended the law argued that "Russia's not-for-profit sector is in serious need of regulation. It still hasn't developed legal underpinnings to assure transparency of expenditures, operations or founder information - all of which are crucial for societal trust and civil society development".⁷ In other words, while being somewhat critical of the new NGO law, some civil society actors argued that there were still many opportunities for independent civic activism. In their view, civil society should not necessarily be seen as actively opposing the existing regime. Instead, civil society organizations should act as a mediator between the state and its citizens, and be an active participant in a dialogue with the authorities.⁸

Inspired by this debate, I argue that in recent years Russia's civil society has grown significantly stronger and more vocal, demonstrating a great potential for social and political mobilization. Dissatisfied with state policies, the Russian citizens started organizing in various grassroots movements to address various social issues. This new wave of civic activism originated largely online, uniting people of various backgrounds and interests. The majority of participants in these movements were critical of government actions, but did not regard the state as an enemy. In contrast to the "classic" civil society organizations and movements such as *Yabloko*, The Other Russia, or Solidarity, which operated in the political realm and positioned themselves as a force opposed to the existing competitive authoritarian structure, these new civil society groups began their journey in the social realm. They have since grown popular and influential, raising not only social issues but issues related to the lack of adequate political and social reforms, weak state capacity and the corruption of state bureaucracy.

⁵ See, for example, Human Rights Watch, "Russia: Revise NGO Law to Protect Rights", available at <http://www.hrw.org/ru/news/2009/05/13/russia-revise-ngo-law-protect-rights> [accessed April 30, 2010]. Or William Fisher, "Russia: NGO Law Could Strengthen Civil Society, Group Argues," *InterPressService* (New York, 25 January 2006), available at <http://ipsnews.net/news.asp?idnews=31908> [accessed April 6, 2010].

⁶ Claire Bigg, "Russia: NGOs Say New Bill Threatens Civil Freedom," *Radio Free Europe/Radio Liberty* (November 23, 2005), available at <http://www.rferl.org/content/article/1063212.html> [accessed April 6, 2010]. Also Human Rights Watch, "An Uncivil Approach to Civil Society" (June 17, 2009), available at <http://www.hrw.org/en/reports/2009/06/16/uncivil-approach-civil-society-0> [accessed April 6, 2010]. And Svetlana Marinova, "Russia: No Country For Charitable Souls," *Eurasianet.org* (8 January 2008), available at <http://www.eurasianet.org/departments/insight/articles/eav080108.shtml> [accessed April 7, 2010].

⁷ This view was expressed by Sharon Tennison, who was the head of a Moscow-based NGO, the Centre for Citizen Initiatives. See William Fisher, "Russia: NGO Law Could Strengthen Civil Society, Group Argues," <http://ipsnews.net/news.asp?idnews=31908> [accessed April 6, 2010].

⁸ Marcia A. Weigle, "On the road to the civic forum: State and civil society from Yeltsin to Putin," pp. 117-146. Also Brian D. Taylor, "Law enforcement and Civil Society in Russia," pp. 193 – 213.

I will illustrate this broad trend by analyzing the origins and development of two volunteer movements, the NGO *Advita* and a volunteer movement formed on the website of one local parents' forum in Saint-Petersburg.⁹ The initial goal of these movements was to help families of children diagnosed with cancer to overcome the everyday psychological, legal and financial difficulties associated with treatment. However, as these movements grew, they could no longer remain apolitical. They started raising various issues related to health care, calling on people to get involved and demanding health care reform and the passage of effective drug and health care policies.

This recent trend is important, as until recently, the role of civil society in the evolution of the Russian health care system has been largely insignificant. As Diane M. Duffy correctly noted, in the 1990s the Russian health care system lacked any home-grown voluntary organizations beyond those with international connections, such as the Red Cross, the Cancer Society and the Heart Association.¹⁰ According to her observations, voluntary contributions were limited to donations from government-owned enterprises.¹¹ This meant that the policy agenda was established at the center, with little involvement of civil society and few feedback mechanisms to accommodate people's needs and concerns. The citizens passively accepted the conditions, or used their own personal resources to obtain what they needed. As Duffy noted in 1999: "A successful health program needs a civil society that sees health care as valuable, a health system responsive to the public's needs, and a political system with adequate leadership skills and motivation to develop and implement a realistic national health plan that will achieve the health outcome goals for the nation. As things currently stand in Russia, all are underdeveloped."¹² In light of this, the recent mobilization of civil society in response to the ongoing health care crisis is a socially and politically important development. It indicates that the process of social capital accumulation in Russia is underway, thus instilling some hope in Russia's future.

The paper proceeds as follows. In the next section I will explain the overall state of the Russian health care system with particular emphasis on cancer care. I will then discuss the origins and development of the civil society organizations working in the field of pediatric oncology in Saint-Petersburg and elsewhere in Russia. The paper concludes with a short summary and an outlook for the future. With this research topic, I hope to shed new light on developments in the Russian health care sector, and deepen our understanding of Russian civil society.

2. Soviet and post-Soviet health care system in Russia: a brief overview

To understand the state of health care in contemporary Russia, a brief examination of the Soviet past is required. The Soviet health care system was centralized, hierarchically organized and financed from general government revenues. The Soviet government claimed to provide health services free of charge to the whole population, irrespective of social and economic status. In practice, however, payment for health care services and especially medicines was common. It is true that some groups of the population including outpatients receiving treatment for a defined list of communicable and chronic diseases (e.g. tuberculosis, syphilis, dysentery, diabetes, cancer, schizophrenia and epilepsy) and children

⁹ See their websites at www.Advita.ru and www.littleone.ru.

¹⁰ Diane M. Duffy, "An Assessment of Health Policy Reform in Russia," in *Medical issues and health care reform in Russia*, edited by Vicki L. Hesli and Margaret H. Mills (Lewiston, New York: Edwin Mellen Press, 1999), p. 41.

¹¹ *Ibid.*, p. 41-42.

¹² *Ibid.*, p. 42.

under one year of age were exempt from payment for medicine. Certain groups of the population such as WWII invalids and persons receiving a personal pension were offered reductions in the cost of prescribed medicines. All other patients were expected to pay for medicine.¹³

The organization of the Soviet health care system was developed and monitored by the Ministry of Health, which was responsible for the planning and control of all public health activities including assessing the state of health of the people, setting national health standards, determining populations' need of medical care, medical equipment and pharmaceuticals, and conducting medical research and training.¹⁴

Health care was provided at three different levels. At the lowest level, medical district units – often referred to as polyclinics – were set up. These were comprised of groups of physicians and nurses, who were responsible for primary health care in the medical district of 3,000-40,000 residents. Their responsibilities included diagnosis and treatment of common diseases, transfer of patients to district hospitals, control and surveillance of hygienic conditions and preventive immunization.¹⁵

At the district level, hospitals served a population of 70,000 to 150,000 residents, and were responsible for diagnosing and treating diseases, and a follow-up. Specialized health care institutions were located primarily in regional centers and in the capitals of the republics. They included central hospitals with a wide range of specialized departments and dispensaries (e.g. oncological, tuberculosis dispensaries).¹⁶ Medical educational and research institutions were also located in regional and republican capitals.¹⁷

In the Soviet Union, the first contact for a person with symptoms was the general practitioner in a local polyclinic. If cancer was suspected, the patient was referred to the district hospital for diagnosis. The district oncologist performed clinical diagnosis of malignant and non-malignant neoplasms, and if needed referred the patient to the regional oncological dispensary for specialized diagnosis and treatment.¹⁸

The oncological dispensary was responsible for exact diagnosis and treatment of cancer. Each oblast and republic had at least one oncological dispensary. Oncological dispensaries consisted of an outpatient department and an inpatient facility of some 200-300 beds.¹⁹ Specialized departments included radiology, chemotherapy, surgery, X-ray, and others. For diagnosis and treatment of difficult tumors, such as a tumor of an eye, patients were referred to specialized institutions at the federal level (i.e. The Institute of Oncology) or to clinics attached to research institutes.²⁰ After treatment, follow-up was provided by the local district hospital outpatient department.

In principle, the Soviet cancer care system looked quite comprehensive: the vertical system was meant to ensure that everyone, even in remote parts of the Soviet Union, had access to an oncologist. This, together with a great supply of hospital beds and free medicine provided to cancer patients at the state's expense, meant to illustrate the comprehensiveness of the Soviet health care system, and cancer care system specifically.

¹³ R.A. Winkelmann, et al., Cancer registration techniques in the New Independent States of the former Soviet Union (Lyon: IARC Technical Report Nr. 35, 1998), p. 16.

¹⁴ Ibid.

¹⁵ Ibid., p. 18.

¹⁶ Ibid.

¹⁷ Ibid.

¹⁸ Ibid., p. 22.

¹⁹ Ibid., p. 22-23.

²⁰ Ibid.

In practice, however, the picture looked gloomier. Low salaries and absence of incentives, as well as low quality of free medical services, contributed to the rise of corruption and bribery.²¹ In addition, low quality of pharmaceuticals, insufficient medical equipment and poor maintenance of health care facilities significantly undermined the quality of cancer care in the Soviet Union. Even though the official cancer statistics were imprecise and never publicly revealed, rough estimates showed that in the Soviet Union the survival rate for children with leukemia or lymphomas did not exceed 5-10%.²²

With the collapse of the Soviet Union, a period of radical economic and political reforms began. The liberalization process saw radical reforms in the social security, education and health care sectors. Health care reform began as early as 1991, when the Yeltsin government initiated mandatory and voluntary health insurance programs and introduced a special tax to fund the mandatory component. The compulsory medical insurance was to cover the necessary minimum of medical services, whereas the voluntary covered all other expenses.²³ The government has also decentralized the health care sector and shifted a large portion of state expenditures to the regional level, including those for paramedics, medications, primary health clinics, hospitals and diagnostic centers.²⁴ All other functions such as control of salaries and the responsibility for health promotion and oversight were left within the jurisdiction of the Federal Ministry of Health and Social Protection. These changes resulted in significant decentralization of the Russian health care system with the responsibilities shared between several regional and federal institutions.

The reassignment of the financing of health care programs to the regional level contributed to a dramatic decline in their quality. Poor regions lacked sufficient financial resources, and were unable to provide an adequate level of health care to its residents. Fiscal transfers from the federal government helped little due to their small size and irregularity. As a result, shortages of every kind of resource were dramatic. Bed sheets, bandages, food, soap, medicine, and even medical equipment often had to be purchased and delivered to the hospital by the patient or his/her relatives. Fundamentally, it meant that the quality of public health care and access to the public health care system were becoming significantly unequal.

The crisis has also affected the medical personal. Strikes and demonstrations by literally hungry health care providers were widespread through all of the 90s.²⁵ Those who could leave, left the state-run health care sector to set up private medical clinics. Dental, gynecological, eye, beauty and other private clinics sprang up all across Russia. This offered those Russian citizens who were in a position to pay for the health care services some choice when choosing a health care provider. At the same time, the commercialization of the Russian health care sector contributed to greater stratification of the Russian society and, inadvertently, lowered standards of medical care in state-run polyclinics and hospitals, as

²¹ Michael Ryan, Doctors and the State in the Soviet Union (Houndmills: The Macmillan Press, 1989), pp. 19-35. R.A. Winkelmann, et al., p. 15.

²² The Donors-For-Kids Group, "Frequently Asked Questions Concerning Child Cancer and Blood Diseases," compiled by Marina Molchanova and edited by Dr. Mikhail Maschan, available at <http://www.donors.ru/page.php?id=20880> [accessed May 8, 2010]. "Detskii rak – ne fatal'nyi prigovor. Esli my vmeste budem spatat' nashikh detei!" [Pediatric cancer is not a lethal verdict. If we fight it together!], Rosbalt (St. Petersburg, 20 February 2006), available at <http://www.rosbalt.ru/2006/2/20/244373.html> [accessed April 15, 2010].

²³ Tishchenko P. D. and Yudin B. G., "Toward a Bioethics in Post-communist Russia," in Knowledge, Understanding, Skill (20 April 2008), available at <http://www.zpu-journal.ru/en/articles/detail.php?ID=329> [accessed March 28, 2010].

²⁴ Diane M. Duffy, "An Assessment of Health Policy Reform in Russia," in Medical Issues and Health Care Reform in Russia, p. 28.

²⁵ Tishchenko P. D. and Yudin B. G., "Toward a Bioethics in Post-communist Russia," <http://www.zpu-journal.ru/en/articles/detail.php?ID=329>.

many doctors left for better paid positions in the private sector. In short, the health care reform launched in the context of a deep economic crisis, contributed to the worsening of the situation in the state-run health care sector and furthered the commercialization of health care provision. Let us now review the situation with cancer care provision in Russia during the 90s.

3. Cancer care in Russia: institutional structure, trends and problems

The collapse of communism, the economic crisis and the subsequent health care reform left a controversial imprint on Russia's cancer care system. On the positive side, closer collaboration with the West allowed the Russian oncologists to learn from their Western colleagues. By following the more effective Western chemotherapeutic protocols, the Russian oncologists were able to improve cancer treatment and hence raise the survival rate for cancer patients to roughly 50%. While better than under communism, these figures nonetheless did not match the effectiveness of cancer treatment of children in the West, where the survival rate usually exceeds 80%.²⁶

By all other indicators, the situation in fact turned out for the worse. Fundamentally, the health care reform launched in 1991 did not alter the old Soviet system of cancer care, but added additional problems. Already plagued by Soviet legacies such as poorly paid medical personal and low quality of pharmaceuticals and health care services, the Russian cancer care system was faced with a number of new challenges such as inadequate financing and rapidly deteriorating provision of cancer care. Insufficient funding and fiscal decentralization resulted in shortages of medicine in hospitals, outdated medical equipment, poor maintenance of health care facilities and poor hygienic conditions. Regional governments found it extremely difficult to finance and maintain their hospitals and medical facilities, update their medical equipment, and provide hospitals and their populations with free medicines. Even hospitals and research institutes funded from the federal budget were in need of renovation and experienced shortages of medicines and medical equipment. Finally, the poor organization of cancer care provision has significantly complicated the access to treatment quotas and necessary cancer care services for ordinary Russians.

Officially, cancer treatment was included in the compulsory insurance program, which meant that all costs of cancer treatment were to be borne by the state. The reality, however, was different. Upon admission to a hospital, a patient and his/her parents usually faced a number of problems, including the catastrophic shortages of state-funded medicines. Many chemotherapy medications were simply lacking in hospitals, thus leaving the Russian cancer patients – and in our case, parents of sick children – no choice but to seek money elsewhere. Virtually no oncology center in Russia was spared. Regional cancer centers as well as the top oncology centers in Moscow and Saint-Petersburg faced shortages of required medicines.²⁷ As a result, parents and relatives of children were forced to seek funds and buy the required medicines themselves. The situation was so dramatic that in some instances,

²⁶ The Donors-For-Kids Group, "Frequently Asked Questions Concerning Child Cancer and Blood Diseases," <http://www.donors.ru/page.php?id=20880>.

²⁷ I am referring to such top cancer institutions as the Russian Children's Clinical Hospital (RDKB) located in Moscow, the Oncological Research Institute and the Raisa Gorbacheva Institute for Pediatric Hematology and Transplantology located in Saint-Petersburg. See, for example, "Leading Russian Oncology Center Faces Shortage Of Medicine," *Radio Free Europe/Radio Liberty* (8 December 2008), available at <http://www.rferl.org/content/Leading-Russian-Oncology-Center-Faces-Shortage-Of-Medicine/1357672.html> [accessed May 1, 2010].

shortages of medicine or delivery delays forced doctors to appeal to the people in search of urgent help and financial assistance.²⁸

The quality of cancer care was further compromised by the fact that the government did not cover the costs of several additional vitally important drugs such as the drugs required in the pre- and post-chemotherapy periods, including the anti-fungal drugs Ampholip, Cancidas, and Vifend.²⁹ These medications helped the patients cope with severe infectious complications, which often occurred as a result of low immunity of children after chemotherapy, poor hygienic conditions in many Russian cancer centers, or both. Of note, most of these hospital infections are fatal if not treated in time, and many of them resist treatment with ordinary drugs. Moreover, some of these drugs are intolerably toxic for a patient who is already seriously affected by the oncological disease. This is the reason why doctors often prescribe children advanced, last-generation antibacterial, antiviral, and especially anti-fungal medicines.³⁰ These medications are very expensive: an average price of one pack containing 14 capsules of Vifend, a vital anti-fungal drug is over \$1000 per pack; a vial of Ampholip costs more than \$200; and a cost of one vial of Cancidas amounts to \$600.³¹ The entire course of treatment with these drugs usually lasts for several weeks or even months, forcing families of cancer stricken children spend many thousands of dollars on these medications.

The children, whose parents cannot buy these expensive drugs, have to be satisfied with cheaper medicines such as Valtrex, Zovirax, Timentin, Cardioxane, Roaccutane, Ursolfalk, etc., officially supplied by the state. The problem is not only that these drugs are extremely toxic and considerably less efficient in fighting complications, but that their supply is also interrupted.³² In such cases, the parents again must pay for such drugs themselves, and it often turns out that they cannot raise these smaller sums.

The situation is further complicated by the fact that the government does not cover the costs of some special diagnostic and auxiliary procedures such as MRI and CT scans, some laboratory tests, precise mapping of a tumor prior to radiotherapy (so-called pre-treatment simulation), etc. necessary for the successful treatment of the disease. The costs of these procedures are usually borne by the families. Finally, due to a chronic shortage of blood in the Russian hospitals, relatives of patients are forced to buy blood in other hospitals and/or seek blood donors, often offering them additional payment on top of that paid by the state. In some cases, the medical staff has no alternative but to give their own blood to patients.

The situation of families whose children are referred to national cancer care centers in Moscow or Saint-Petersburg because of the complexity and aggressiveness of their disease is even more alarming. In such families, mothers usually leave their jobs and relocate with their children. As for the fathers, many cannot bear the difficulties and break down, often leaving their families. Even those who make a concerted effort to secure the necessary funds seldom succeed if the family comes from a poor region with a high unemployment rate and low average income.³³ Quite often these families even sell their apartments or houses to

²⁸ See, for example, The Aleksander Men Help Group working at the Russian Children's Clinical Hospital, "Help Us Save the Children. Patients of the Oncology Department urgently need drugs for chemotherapy," available at http://deti.msk.ru/en/programma4_en.htm [accessed April 16, 2010].

²⁹ The Donors-For-Kids Group, "Important information about the financing of pediatric medicine in Russia and why fundraising is vitally necessary," available at <http://www.donors.ru/page.php?id=20921> [accessed May 1, 2010].

³⁰ Ibid.

³¹ Ibid.

³² Ibid.

³³ Ibid.

cover the costs of expensive drugs or treatments such as bone marrow transplantation. During the months-long stay at the hospital, these families exhaust their means to such an extent that even buying food and clothes becomes a real problem. With shortages of medicines common even in top cancer centers, families usually require financial assistance.

For many children with complex and aggressive forms of leukemia, lymphoma, etc., the only option for survival is bone marrow transplantation (BMT). According to Liubov Fregatova, a Professor in the Department of Hematology, Transfusiology and Transplantology at Saint-Petersburg State Medical University, each year there are at least 200 Russian children and 400 adults who require bone marrow transplantation.³⁴ These numbers do not include patients from the post-Soviet republics, who, due to the lack of qualified doctors and medical equipment in their home countries, are forced to seek help abroad, primarily in Russia.

Until recently, only three hospitals in Russia performed bone marrow transplantations. There are waiting lists, and it often takes months before transplantation to one or another patient can be made. But BMT must often be performed quickly and without hesitation if the disease is especially aggressive and there is danger of relapse.³⁵ There have been several tragic cases with Russian children: some die while waiting for the transplantation, although a donor had already been found and funds with the help of private sponsors had been raised.³⁶

The approximate total cost of each transplantation conducted in Russia is \$60,000-80,000, and the Russian government does not cover the entire sum. Among the costs not covered by the Russian state is the search and delivery of bone marrow donations to Russia. Problematic is that only about 20% children with cancer in Russia have suitable related donors of bone marrow among parents, siblings, etc.³⁷ This means that the majority of children must have transplantations from unrelated donors. Such a donor should be found in a marrow donor registry according to immunological compatibility of tissues. But Russia has no marrow donor bank of its own, which means that the search for an unrelated donor must be performed in foreign registries, such as that of Stefan Morsch Stiftung in Germany.³⁸ The cost of a donor search in such a registry, followed by donor activation (harvesting and transportation of bone marrow or stem cell graft), is about 15,000-17,000 euro.³⁹ As mentioned, this money is not granted by the state and must be donated by private sponsors.

The issue has been red-flagged by civil society organizations in Moscow and Saint-Petersburg which have set up a number of autonomous bone marrow registries in Russia.⁴⁰ However, as Professor Fregatova states, “all these databases are not connected to each other. And thus, we cannot speak about having a viable organization. A bone marrow register is, in the first place, an organization operating according to specific legal rules and procedures. In Russia, none of the problems associated with such transplantations has been addressed so

³⁴ Liubov' Arkus, “Esli ne my, to kto?” [If not us, then who?], *Seans* (Nr. 23/24), available at <http://seance.ru/n/23-24/ne-o-kino/arkus-bлаго/> [accessed May 3, 2010].

³⁵ The Donors-For-Kids Group, “Important information about the financing of pediatric medicine in Russia and why fundraising is vitally necessary,” <http://www.donors.ru/page.php?id=20921>.

³⁶ Ibid.

³⁷ Liubov' Arkus, “Esli ne my, to kto?,” <http://seance.ru/n/23-24/ne-o-kino/arkus-bлаго/>.

³⁸ The Donors-For-Kids Group, “Important information about the financing of pediatric medicine in Russia and why fundraising is vitally necessary,” <http://www.donors.ru/page.php?id=20921>.

³⁹ Ibid.

⁴⁰ Liubov' Arkus, “Esli ne my, to kto?,” <http://seance.ru/n/23-24/ne-o-kino/arkus-bлаго/>. Also “Registr potentsial'nykh nerodstvennykh donorov gemopoeticheskikh kletok” [Registry of possible unrelated donors of hematopoietic cells], available at <http://Advita.org/donor.php> [accessed May 3, 2010].

far. Donors don't have a legal opportunity to insure their lives or be paid for their service. Transportation of transplant material across the Russian border is equally a grey and legally unregulated area."⁴¹ In contrast to other countries, where all aspects of bone marrow transplantation are regulated and financed by the state, in Russia the role of the state in solving these problems is close to zero.

Some Russian patients with cancer need treatment abroad. Sometimes this is due to unique treatment procedures that are already used in foreign hospitals but not yet available in Russia. In other cases, the reason is simply the shortage of hospital beds in Russian cancer centers. Since bone marrow transplantations are done in only a few centers across Russia, and each center has a limited number of beds, many patients have to wait, sometimes many months.⁴² In such situations, the only way to better a child's chance for survival is to send them abroad for the transplantation. This obviously raises the cost of treatment. A bone marrow transplantation in Israel, which is one of the most affordable ways out, costs over \$100,000 for each patient.⁴³ The Russian Ministry of Public Health usually provides two-thirds of the required sum if the child falls within the so-called quota for life-saving treatment abroad, but one-third must be raised by the patient's family. In other cases, the child's family must raise the whole sum. Without private sponsorship, it is usually impossible.

In short, the provision of effective cancer treatment in Russia is complicated due to several problems that have affected the existing cancer care system for decades. First, there is a pressing need in modern cancer centers to satisfy the demand for additional hospital beds, especially as regards transplants. As well, the majority of the existing cancer centers are in need of regular maintenance and new medical equipment. Second, the legal base of the existing cancer care system must be changed to accommodate the needs of the cancer patients. In particular, there is an urgent need to update the existing list of state-funded medicines with new, vital medications, without which the successful treatment of cancer is virtually impossible. Funds are being wasted on generic drugs, which are piling up in Russian pharmacies because oncologists refuse to prescribe such toxic and ineffective medications to their patients. Further, the government should increase the number of state quotas issued for treatment of cancer patients and simplify the application process for receiving a state quota. It should also raise the nominal value of such quotas to cover the expenses associated with cancer treatment, including bone marrow transplantations. Likewise, the Russian government should invest in creating a national register of bone marrow donors and formulate a clear legal base, which would regulate the search and transport of bone marrow transplants, as well as address and protect the interests of donors and recipients.

Finally, there is the issue of terminally ill patients. Russian law does not contain any reference to providing adequate palliative care to such patients, and the Russian health care system is lacking in medical personal qualified to treat such patients. As of today, Russia has no stationary pediatric hospices for cancer patients. It is true that mobile pediatric hospices exist, but the range of their medical services is limited as they usually lack professional training and are unauthorized to prescribe narcotic pain killers to such patients. This means that parents of terminally ill children are forced to buy narcotics from illicit sources.

⁴¹ Liubov' Arkus, "Esli ne my, to kto?," <http://seance.ru/n/23-24/ne-o-kino/arkus-bлаго/>.

⁴² The Donors-For-Kids Group, "Important information about the financing of pediatric medicine in Russia and why fundraising is vitally necessary," <http://www.donors.ru/page.php?id=20921>.

⁴³ Ibid.

To address these problems, many Russian citizens have joined grassroots movements. In the beginning, the majority of these civic movements did not have any political influence or access to any regular funding, relying instead on individual donations from ordinary citizens. However, as these movements grew, their financial situation has had improved. Moreover, their growing popularity has allowed them to address the problem at the national level, thus spreading public awareness and pressuring the government to respond. Arguably, with the growth of the internet and other communication technologies, the popularity of such movements will only increase. In my opinion, the development of such grassroots movements is one of the key preconditions for the emergence of a strong civil society and further democratization and liberalization in Russia. I will illustrate this trend by discussing two volunteer movements in Saint-Petersburg, and proceed to situate this trend within the broader Russian context.

4. Accumulation of Social Capital and the Birth of Genuine Civil Society in Russia

Among the first movements supporting families of children with cancer in Saint-Petersburg was a local movement *Advita*, started by a software engineer who lost a friend to cancer, and a group of Russian oncologists from Saint-Petersburg. *Advita* was registered as a charity fund in 2002. *Advita* sees its mission as assisting families affected by cancer to bear the costs of treatment, to raise funds for procurement of medicines and medical equipment, and to provide families and patients with legal, psychological and social help during pre- and post-operative periods.⁴⁴ *Advita*'s ultimate goal is to reduce the mortality rate among Russian citizens suffering from various types of cancer and blood disorders, to draw public attention to the necessity of developing a Russian Bone Marrow Registry, and to raise the qualifications and practical experience of Russian hematologists, oncologists and transplantologists.

Advita's staff consists of only 5 permanent employees, who are responsible for running the 24/7 blood donor call center and some basic administrative work. The majority of *Advita* members are non-paid volunteers.⁴⁵ Currently, *Advita* has between 100 and 150 permanent volunteers. The social and age composition of these volunteers is quite diverse. It encompasses men and women, old and young, poor and rich, people of different professions and nationalities.

One group of volunteers is responsible for maintaining and updating the *Advita* website, posting updates on internet-based social networks, communicating with the media, advocating for blood donations, and organizing various social events aimed at raising funds and public awareness of the problems faced by cancer patients. Other volunteers are assisting the families of sick children. These volunteers play with children, help families purchase food and clothes, search for required medications, and assist in dealing with the bureaucracy of various health care departments. These are the people who assist families in overcoming their everyday social, bureaucratic, psychological and financial problems.

One should also mention the thousands of donors who donate money and blood, viewing it as their civic duty. According to Elena Gracheva, an active *Advita* volunteer and coordinator, the majority of donors come from poor and low middle families – students, pensioners, women and disabled people regularly donate between 100 and 500 rubles.⁴⁶ It is they who allow *Advita* to buy medicine, food and rent housing for the patients and their

⁴⁴ *Advita*, "Our targeted programs," available at <http://Advita.org/en/fund.php> [accessed May 10, 2010].

⁴⁵ Interview with Elena Gracheva, 28 August 2008, Saint-Petersburg, Russia.

⁴⁶ *Ibid.*

families. However, Gracheva also notes that during the last few years, more and more people from other societal groups have become interested in volunteer work and donations. Engineers, lawyers, journalists and businessmen contact Elena and tell her that they want to participate.⁴⁷

A particularly interesting group of people actively participating in *Advita*'s work is that of Russian-speaking volunteers living abroad.⁴⁸ These people are usually responsible for translating the Russian texts from *Advita*'s website into English, German and French and maintaining the foreign versions of the main website. Among these people, one can often meet professional translators who send patients official documents to hospitals abroad. These volunteers assist the patients and their families, when they arrive for treatment in Germany, Israel and other countries. It is these volunteers who buy medicine at lower prices abroad, arrange its transportation to Russia and donate thousands of dollars on an annual basis.

As the number of volunteers grew, *Advita*'s popularity and influence increased. The new popularity has also led to a growth in their database of sick children. More and more families from all over Russia began contacting *Advita* with their concerns. Desperation among volunteers grew. A realization was growing that only fundamental changes in the overall system of cancer care provision could alleviate this health care crisis. In cooperation with other volunteer movements, *Advita* made an attempt to address these issues in newspapers, on television and in their conversations with regional and state authorities, pushing for changes in current legislation regulating cancer care and drug policies in today's Russia.

In February 2009, *Advita*, *Podari Zhizn'* (Grant Life) and several other NGOs met to discuss the most urgent problems in the field of cancer care in Russia.⁴⁹ Also in attendance were representatives from the Ministry of Health and Social Protection of the Russian Federation. Three main topics were addressed at the meeting. First, civil society activists discussed the inefficiency of the existing quota system regulating the provision of cancer care in the top oncology centers. The volunteers emphasized the ineffectiveness of the existing quota system, which offered the regional health departments and the Republican Ministries of Health relative freedom in determining and requesting the required number of quotas from the Ministry of Health and Social Protection. It turned out that the mechanism of quota distribution was not operating effectively, and children from dozens of regions could not receive chemotherapy and bone marrow transplantation on time, because their regions did not apply (or receive) the required number of quotas. Thus, waiting lists for receiving quotas (and hence, treatment) were frighteningly long, leaving parents no choice but to look for alternative places for treatment, usually abroad. In light of this situation, the Russian Ministry of Health and Social Protection was asked to review and improve the existing system of quota and to better equip the regional cancer centers, so as to minimize the number of patients having to travel to Saint-Petersburg or Moscow.⁵⁰

The second issue discussed at the meeting concerned the problem of the so-called orphan drugs. As mentioned earlier, there are a number of vitally important drugs that are

⁴⁷ Ibid.

⁴⁸ See, for example, Advita Fund USA at <http://www.Advitausa.org/>.

⁴⁹ "V Moskve obsudiat samye ostrye problemy detskoj onkologii v Rossii" [The most urgent problems in pediatric oncology will be discussed in Moscow], *FarmAnalitik* (9 February 2009), available at <http://fbr.info/content/view/714947/138/> [accessed May 15, 2010]. Also Advita, "Osnovnye problemy detskoj onkologii" [The most urgent problems in pediatric oncology], available at www.Advita.ru [accessed April 28, 2010].

⁵⁰ Advita, "Osnovnye problemy detskoj onkologii," www.Advita.ru.

prescribed by oncologists, even though they are not registered in Russia. In the majority of cases, such drugs are taken into the country illegally with the help of volunteers, friends and relatives living abroad. Abandoned by the state, people collect money, seek opportunities to buy drugs at cheaper prices, look for people willing to smuggle these drugs into the country, and pay 30% of the costs in form of taxes and fees at the border. NGOs called on the Ministry of Health and Social Protection to pass changes to the current legislation, introducing the concept of orphan drugs and formally regulating their transportation and distribution in the Russian Federation.⁵¹

The third problem discussed at the meeting was related to the issue of palliative care. As mentioned, Russia does not have a system of pediatric palliative care to assist children who are in the terminal stages of cancer. Russian children in the terminal stages of cancer are most often discharged from cancer centers and sent home, where their parents face the horrible reality of not being able to provide adequate palliative care.⁵² The Russian volunteers called on the Russian authorities to address this issue and change the current legislation also.

The dialogue between the third sector and the government looked quite promising. However, solving these problems turned out to be an extremely complicated and exhausting process. Many civil society organizations are jointly lobbying the regional and federal authorities to change the legislation regulating palliative care and circulation of narcotic-containing drugs in Russia.⁵³ The difficulty in modifying the existing system of palliative care stems from an overlap in Russian legislation regulating the circulation of narcotic drugs. Whereas the ministry of Health and Social Protection allows prescription of narcotic-containing drugs in palliative care, a federal law regulating their use in the Russian Federation grants the authority to issue such prescription only to those hospitals and clinics which fulfill the prescribed security requirements (i.e. walls should be of particular thickness, windows should be grilled, etc.). In an effort to solve this problem, the NGOs proposed selecting a number of polyclinics that satisfy the prescribed security requirements imposed by the government. These polyclinics could receive the authorization to issue prescriptions for narcotic-containing drugs to all patients from a particular region. These polyclinics would also have their own emergency ambulances.⁵⁴ The ongoing construction of the first children's hospice in Saint-Petersburg seems promising, with *Advita* volunteers overseeing the process and reporting it to the broader civic community.

In regards to orphan drugs, little progress has been made. However, the civic groups continue to lobby the government in hope that changes to the recently passed legislation will be made. During preparation of the pharmaceutical market bill last year, several Russian NGO's including *Advita* appealed to the government to make provisions for orphan drugs in

⁵¹ Ibid.

⁵² Ibid.

⁵³ "Fond Advita napravila predlozheniia glavnomu onkologu" [Advita made a proposal to the chief oncologist], All North-West of Russia (Saint-Petersburg, 14 October 2008), available at <http://spb.allnw.ru/news/82812> [accessed May 8, 2010]. "Detskii khospis. Dolzhen byt'" [Pediatric hospice will be built], available at <http://www.forum.littleone.ru/archive/index.php/t-627343.html> [accessed May 9, 2010]. "Neizlechimo bol'nye deti zhdu otkrytiia khospisa i pomochshi metsenatov" [Terminally ill children are awaiting the opening of the children's hospice and patronal assistance], 5-yi Kanal. Peterburgskii chas [The Fifth Channel. Saint-Petersburg in One Hour], available at <http://www.spbtv.ru/new.html?newsid=3081> [accessed May 10, 2010]. "Saint-Petersburg. Kruglyi stol 'Khospisy Peterburga,'" [Saint-Petersburg. Roundtable 'Hospices of Saint-Petersburg'], Rosbalt (9 October 2008), available at <http://www.rosbalt.ru/2008/10/09/530446.html> [accessed May 9, 2010].

⁵⁴ "Saint-Petersburg. Kruglyi stol 'Khospisy Peterburga,'" <http://www.rosbalt.ru/2008/10/09/530446.html>.

terms of introducing a financing, licensing, and procurement mechanism.⁵⁵ Thousands of people signed the petition.⁵⁶ Nonetheless, the bill, passed on 31 March 2010, did not contain any mention of orphan drugs. Nonetheless, some changes were made. For example, the new bill simplified the import of non-licensed in Russia drugs. As of now, all drugs imported to for personal use will be cleared within five days. The buyer will receive an electronic document containing a digital signature, allowing him/her to import the drug to Russia. Russian patients and their relatives no longer need to secure a special permission to import the drug to Russia. However, the bill failed to address major issues such as financing. The civil society reacted by organizing and drafting another petition, this time addressed to the President of the Russian Federation Dmitrii Medvedev, requesting the legalization of orphan drugs and simplification of their registration and transportation. More than 50 NGOs and grassroots movements called on the President to amend the bill.⁵⁷

It is no exaggeration to state that these activities would not be possible without the help of internet. The role of the internet in the development of Russian civil society is indisputable. Although some scholars have questioned the positive impact of internet on social cohesion and the development of civil society, the evidence from the post-Soviet societies shows that the internet has empowered the masses and strengthened the bonds of the civic community. The internet has offered people the chance to find and participate in communities of interest, thus allowing for greater civic engagement. This is evident in my next example discussing the origins and evolution of one local internet forum in Saint-Petersburg.

The website littleone.ru was developed by one young mother from Saint-Petersburg in 2000. Interested in communication with other young parents, she created a website where she could meet other mothers and discuss issues related to children and family. Being the first such family-oriented website in Saint-Petersburg, littleone.ru quickly became popular.⁵⁸ Here the first local help forum was created, where people could volunteer and join various grassroots initiatives. As the number of topics grew, volunteers organized into groups that addressed various themes including orphaned children, abandoned elderly citizens, oncology patients, etc. Often, citizens participated in several groups, spending time with orphans in orphanages or pensioners in retirement homes. Some topics on the forum list were temporary and appeared in response to some tragic events and situations, such as the 2004 Beslan tragedy, after which many Saint-Petersburg residents invited children and their parents from North Ossetia to visit Saint-Petersburg. Other topics such as “Cancer center of the 31st City Hospital” became permanent, with thousands of people contributing their time, money and energy to assist children and their families during a difficult period in their lives.⁵⁹

⁵⁵ Zulaikha Sesay, “Access to Orphan Drugs in Russia is Limited, Says Patient Group,” *IHS Global Insight Daily Analysis* (26 February 2010), accessed via www.factiva.com.

⁵⁶ “Pod obrachsheniem za legalizatsiiu “orfannykh” preparatov podpisalis’ 21 tysiacha rossiiian” [21 thousand people signed the petition in support of the orphan drugs legalization], *Agenstvo Sotsial’noi Informatsii* [Agency of Social Information] (Moscow, 7 April 2010), available at http://www.asi.org.ru/asi3/rws_asi.nsf/va_WebPages/538509DC70A90A1AC32576F7002603B3Rus [accessed April 27, 2010].

⁵⁷ Ibid. See also “Obrachshenie k Prezidentu. Gosudarstvo – eto my” [Appeal to the President. The state, it is we], available at <http://to-president.livejournal.com/> [accessed April 22, 2010]. See also Natalia Telegina and Anna Rudnitskaia, “Sirotskoe golosovanie” [The orphan drugs ballot], *Russkii Reporter* (Moscow, 25 March 2010), available at http://www.rusrep.ru/2010/11/news_medicina/ [accessed April 22, 2010].

⁵⁸ “Vtoroi rebenok” [The second child], in *Nashi dengi* [Our money] (Saint-Petersburg, Nr. 27, 2006), available at <http://www.nashidengi.ru/issues/676/vtorojrebenok/> [accessed April 24, 2010].

⁵⁹ “Detskoe otdelenie 31-oi GB” [The Children’s Unit at the 31st City Hospital], available at <http://www.forum.littleone.ru/showthread.php?t=2522700> [accessed May 5, 2010].

In short, having started as two small grassroots movements, *Advita* and [littleone.ru](http://www.littleone.ru) volunteer movements have developed into powerful voices, capable of raising the social issues at the regional and federal levels. They are not alone in their work. There are several other NGOs working in the same field and collaborating with each other on various issues related to cancer care. For example, in Saint-Petersburg, the oldest NGO assisting cancer patients is the regional non-governmental organization Children and Parents Against Cancer.⁶⁰ The NGO was created in 1998. Since its inception, the organization has evolved into one of the most influential voices for the rights of sick children in Russia. Like *Advita*, the organization performs several tasks. It organizes fundraising events to assist cancer patients, educates parents of children affected by cancer about their rights, and appeals to governmental authorities and other official bodies to assist parents in the acquisition of necessary medicines.⁶¹

In Moscow, volunteer movements including Donors For Kids, Happy World, Nastenka Fund, They Believe, *Podari Zhizn'* (Grant Life) and many others have emerged over the past eight years.⁶² Given the ongoing lack of trust in NGOs among the Russians, many volunteers believe that the participation of well-known celebrities is the only way to resolve the problem. A telling example is the case of respected actress, Chulpan Khamatova.⁶³

Khamatova became involved in charity work several years ago when the deputy director of the top oncology center in Moscow appealed to her for help. This is how *Podari Zhizn'* (Grant Life), a foundation to help children with cancer and other life-threatening illnesses, came into being. Today *Podari Zhizn'* is one of Russia's most successful fundraising organizations, having raised nearly 7 million dollars, 57 percent of which came from individuals.⁶⁴

Soon after, a wave of civic activism swept across Russian cities, where literally hundreds of civic initiative groups emerged.⁶⁵ As time passed, cooperation among NGOs and volunteer movements increased. Websites emerged, which collected and organized information about volunteer movements and NGOs working on specific issues across Russia and other post-Soviet republics.⁶⁶ Overall, the outlook is promising: the work of the volunteers has inspired many ordinary people; Russians continue to join volunteer movements in growing numbers. This trend has provided a fertile ground for the development of civil society and accumulation of social capital in Russia, which are indispensable components for successful re-democratization and democratic consolidation.

5. Conclusion: Where to from here?

Fundamentally, there are two ways that this research project can be approached and developed in the future. Seen from a public policy perspective, one of the most pressing

⁶⁰ Please, refer to Children and Parents Against Cancer at http://www.capac.ru/index_e.htm.

⁶¹ Children and Parents Against Cancer at <http://www.capac.ru/index.htm>.

⁶² See, for example, The Donors-For-Kids Group at www.donors.ru, Happy World at www.hworld.ru, They Believe at www.theybelieve.org, *Podari Zhizn'* at www.podari-zhizn.ru, and Nastenka Fund at www.nastenka.ru.

⁶³ Irina Krasnopolska, "Chulpan Khamatova's 'quiet knights' of charity in Russia," *Rossiyskaya Gazeta* (21 April 2009), republished in *Telegraph* at <http://www.telegraph.co.uk/sponsored/russianow/5194278/Chulpan-Khamatovas-quiet-knights-of-charity-in-Russia.html> [accessed May 13, 2010].

⁶⁴ *Ibid.*

⁶⁵ A list of selected volunteer movements and NGOs can be found at *Vsem Mirom* [All Together] at <http://www.vsem-mirom.narod.ru/together/orgki2.htm> [accessed May 12, 2010].

⁶⁶ See, for example, the websites of the following volunteer movements: *Blago* at <http://www.blago.ru/about/> and *Vse Vmeste* [All Together] at <http://www.wse-wmeste.ru/link/>.

issues in Russia and many other post-Soviet states is the desperate state of their post-Soviet health care systems. Given the complexity of the issue, comprehensive research is required to understand the strengths and weaknesses of the existing health care systems, and how they can be modernized and improved.

Yet another angle to look at the problem is to analyze the pattern of relations between the state and civil society, and its broader political and social implications. Seen from this perspective, this project could add to our understanding of the role of civil society in Russian health care, and greatly contribute to the study of democratization across post-Soviet space.

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