3-5 April 2014 Ukrainian Union of Patients Organizations took part at the IV International Kidney Cancer Conference that was held by the International Kidney Cancer Coalition (IKCC).

The event brought together the leaders of patient organizations from around the world to share experiences and work towards global solutions to improve the lives of people with kidney cancer.

This year's conference was attended by representatives from Canada, the United Kingdom, Ukraine, Germany, Netherlands, United States, Uganda, Brazil and others.

The main objectives of the conference were:

- Providing a new scientific information to representatives of patients on current methods of diagnosis and treatment of kidney cancer.
- Identification of common needs, problems and obstacles of organizations that support patients with kidney cancer in the world
- Exchange of ideas, best practices and solutions to enhance the work of patient organizations of kidney cancer.

During the conference participants discussed the following issues:

2. Epidemiology of kidney cancer in the world. The economic and social impact.
3. Scientific developments in terms of early diagnosis of kidney cancer
4. Role of patient organizations in supporting people with kidney cancer
5. Social projects aimed at the prevention and treatment of kidney cancer
6. Dealing with volunteers
7. Issue of “fundraising” in patient organizations
8. Support of care givers
9. Psychological aspects of support for cancer patients
10. Kidney cancer in children
11. The hereditary forms of kidney cancer and others.

About kidney cancer

Kidney cancer is a type of cancer that starts in the cells in the kidney.

The two most common types of kidney cancer are renal cell carcinoma (RCC) and urothelial cell carcinoma (UCC) of the renal pelvis. These names reflect the type of cell from which the cancer developed. The different types of kidney cancer (such as RCC and UCC) develop in different ways, meaning that the diseases have different outlooks (or prognosis), and need to be staged and treated in different ways. RCC is responsible for approximately 80% of primary renal cancers, and UCC accounts the majority of the remainder.

Location within the kidney

Kidney cancer originates in the kidney in two principal locations: the renal tubule and the renal pelvis. Most cancers in the renal tubule are renal cell carcinoma and clear cell adenocarcinoma. Most cancers in the renal pelvis are transitional cell carcinoma.

Signs and symptoms

The most common signs and symptoms of kidney cancer are a mass in the abdomen and/or blood in the urine (or hematuria). Other symptoms may include tiredness, loss of appetite, weight loss, a high temperature and heavy sweating, and persistent pain in the abdomen. However, many of these symptoms can be caused by other conditions, and there may also be no signs or symptoms in a person with kidney cancer, especially in the early stages of the disease.

Factors that can increase the risk of kidney cancer include:

**Older age.** Your risk of kidney cancer increases as you age.

**Smoking.** Smokers have a greater risk of kidney cancer than nonsmokers do. The risk decreases after you quit.

**Obesity.** People who are obese have a higher risk of kidney cancer than do people who are considered average weight.

**High blood pressure (hypertension).** High blood pressure increases your risk of kidney cancer.

**Treatment for kidney failure.** People who receive long-term dialysis to treat chronic kidney failure have a greater risk of developing kidney cancer.
**Von Hippel-Lindau disease.** People with this inherited disorder are likely to develop several kinds of tumors, including, in some cases, kidney cancer.

**Hereditary papillary renal cell carcinoma.** Having this inherited condition makes it more likely you'll develop one or more kidney cancers.

### Epidemiology

Around 208,500 new cases of kidney cancer are diagnosed in the world each year, accounting for just under 2% of all cancers. The highest rates are recorded in Northern America and the lowest rates in Asian and African regions.

The United States' NIH estimates for 2013 around 64,770 new cases of kidney cancer and 13,570 deaths from the disease. In the UK, 8,757 people were diagnosed with kidney cancer in 2008, and the disease caused 3,848 deaths.

The most recent estimates of incidence of kidney cancer suggest that there are 63,300 new cases annually in the EU25. In Europe, kidney cancer accounts for nearly 3% of all cancer cases.

In the UK kidney cancer is the eighth most common cancer in men (5,377 new cases diagnosed in 2008), and the ninth most common cancer in women (3,380 new cases in 2008), giving a male:female ratio of over 3:2. The number of cases of kidney cancer in men in the UK has doubled from 7 per 100,000 to 14.8 per 100,000 between 1975-1977 and 2006-2008. In women the rates have more than doubled over the same period, rising from 3.2 to 7.5 per 100,000.

The incidence of kidney cancer is also increasing in the United States. This is thought to be a real increase, not only due to changes in the way the disease is diagnosed.

**Risks and causes.**

Factors that increase the risk of kidney cancer include smoking, which can double the risk of the disease; regular use of NSAIDs such as ibuprofen and naproxen, which may increase the risk by 51% or may not; obesity; faulty genes; a family history of kidney cancer; having kidney disease that needs dialysis; being infected with hepatitis C; and previous treatment for testicular cancer or cervical cancer.

There are also other possible risk factors such as high blood pressure, which are being investigated by scientists.

In **Ukraine**, the incidence of Kidney cancer in recent years is greatly increased and is presented as 9.8% to 100 thousand people. Chernivtsi region has the lowest rate of the disease. Incidence ratio of men and women is 2:1. The disease occurs in all of age groups and most frequent among persons 40-60 years. The right kidney is affected by the tumor as well as left-hand. Bilateral and synchronous tumors found in 0,5-3,5% cases.
Surgery

Surgery is the initial treatment for the majority of kidney cancers. Surgical procedures used to treat kidney cancer include:

Removing the affected kidney (nephrectomy). Radical nephrectomy involves the removal of the kidney, a border of healthy tissue and the adjacent lymph nodes. The adrenal gland also may be removed.
Nephrectomy can be an open operation, meaning the surgeon makes one large incision to access your kidney. Or nephrectomy can be done laparoscopically, using several small incisions to insert a video camera and tiny surgical tools. The surgeon watches a video monitor to perform the nephrectomy.

Removing the tumor from the kidney (nephron-sparing surgery). During this procedure, also called partial nephrectomy, the surgeon removes the tumor and a small margin of healthy tissue that surrounds it, rather than removing the entire kidney.

Nephron-sparing surgery can be an open procedure, or it may be performed laparoscopically. In some cases, this surgery can be done robotically, which means the surgeon uses hand controls that tell a robot how to maneuver surgical tools to perform the operation.

Nephron-sparing surgery is a common treatment for small kidney cancers. It may also be an option if you have only one kidney. When nephron-sparing surgery is possible, it's generally preferred over radical nephrectomy since retaining as much kidney tissue as possible may reduce your risk of later complications, such as kidney disease and the need for dialysis.

The type of surgery your doctor recommends will be based on your cancer and its stage, as well as your health. Surgery carries a risk of bleeding and infection.

**Treatments when surgery isn't possible**

For some people, surgery isn't an option. In these situations, kidney cancer treatments may include:

Treatment to freeze cancer cells (cryoablation). During cryoablation, a special needle is inserted through your skin and into your kidney tumor using X-ray guidance. Gas in the needle is used to cool down or freeze the cancer cells.

There are few long-term data about the safety and efficacy of cryoablation for kidney cancer. It's typically reserved for people who can't undergo other surgical procedures and those who have small kidney tumors.

Treatment to heat cancer cells (radiofrequency ablation). During radiofrequency ablation, a special needle is inserted through your skin and into your kidney tumor using X-ray guidance. An electrical current is run through the needle and into the cancer cells, causing the cells to heat up or burn.

There are few long-term data about the safety and efficacy of radiofrequency ablation for kidney cancer. Radiofrequency ablation may be an option for people who can't undergo other surgical procedures and those with small kidney tumors.

**Treatments for advanced and recurrent kidney cancer**

Kidney cancer that recurs and kidney cancer that spreads to other parts of the body may not be curable, but may be controlled with treatment. In these situations, treatments may include:

Surgery to remove as much of the kidney tumor as possible. Even when surgery can't remove all of your cancer, in some cases it may be helpful to remove as much of the cancer as possible. Surgery may also be used to remove cancer that has spread to another area of the body.
Drugs that use your immune system to fight cancer (biological therapy). Biological therapy (immunotherapy) uses your body's immune system to fight cancer. Drugs in this category include interferon and aldesleukin (Proleukin), which are synthetic versions of chemicals made in your body. Side effects of these drugs include chills, fever, nausea, vomiting and loss of appetite.

Treatment that targets specific aspects of your cancer (targeted therapy). Targeted treatments block specific abnormal signals present in kidney cancer cells that allow them to proliferate. These drugs have shown promise in treating kidney cancer that has spread to other areas of the body.

The targeted drugs axitinib (Inlyta), bevacizumab (Avastin), pazopanib (Votrient), sorafenib (Nexavar) and sunitinib (Sutent) block signals that play a role in the growth of blood vessels that provide nutrients to cancer cells and allow cancer cells to spread.

Temsirolimus (Torisel) and everolimus (Afinitor) are targeted drugs that block a signal that allows cancer cells to grow and survive.

Targeted therapy drugs can cause side effects, such as a rash that can be severe, diarrhea and fatigue.

Radiation therapy. Radiation therapy uses high-powered energy beams, such as X-rays, to kill cancer cells. Radiation therapy is sometimes used to control or reduce symptoms of kidney cancer that has spread to other areas of the body, such as the bones.

Today the medical community continue to debate over whether surgery is required in the case of small tumor size (≤4 cm). There are proponents of surgical techniques in such tumor size, but there is also a recommendation of monitoring the dynamics of tumor (usually malignant tumors increase during the year by 1 cm).
Rare kidney cancers. Von Hippel-Lindau syndrome (VHL)

What is von Hippel-Lindau syndrome?

Von Hippel-Lindau syndrome (VHL) is a hereditary condition associated with hemangioblastomas (blood vessel tumors) of the brain, spinal cord, and eye. The eye tumors are also called retinal angiomas. People with VHL also have an increased risk of developing clear cell renal cell carcinoma (a specific type of kidney cancer) and pheochromocytoma (a tumor of the adrenal gland). Kidney cysts (a closed sac usually filled with fluid), pancreatic cysts, epididymal cystadenomas (tumors near a man’s testicles), and endolymphatic sac tumors (tumors of the ear, which may cause hearing loss) are also features of VHL.

What causes VHL?

VHL is a genetic condition. This means that the cancer risk and other features of VHL can be passed from generation to generation in a family. The gene associated with VHL is also called VHL. A mutation (alteration) in the VHL gene gives a person an increased risk of developing kidney cancer and other symptoms of VHL. Nearly everyone who has VHL syndrome has an identifiable VHL mutation.
How is VHL inherited?

Normally, every cell has two copies of each gene: one inherited from the mother and one inherited from the father. VHL follows an autosomal dominant inheritance pattern, in which a mutation happens in only one copy of the gene. This means that a parent with a gene mutation may pass along a copy of their normal gene or a copy of the gene with the mutation. Therefore, a child who has a parent with a mutation has a 50% chance of inheriting that mutation. A brother, sister, or parent of a person who has a mutation also has a 50% chance of having the same mutation.

How common is VHL?

It is estimated that about one in 30,000 people has VHL. About 20% of people with VHL do not have any family history of the condition. They have a de novo (new) mutation in the VHL gene.

How is VHL diagnosed?

VHL is suspected when a person has:

Multiple hemangioblastomas (blood vessel tumors) of the brain, spinal cord, or eye, or one hemangioblastoma and kidney cysts, pancreatic cysts, pheochromocytoma, or kidney cancer, or in young patients, VHL is also suspected with multiple bilateral clear cell renal cell carcinoma.

If a person has a family history of VHL, he or she is suspected of also having VHL if the person has any one symptom, such as hemangioblastoma, kidney or pancreatic cysts, pheochromocytoma, or kidney cancer. Genetic testing for mutations in the VHL gene is available for people suspected to have VHL. Nearly all people with VHL will be found to have the genetic mutation once tested.

What are the estimated cancer risks associated with VHL?

The risk of kidney cancer in families with VHL is estimated to be about 40%.

Would the treatment of kidney cancer change if I have VHL?

In general, treatment for kidney cancer is similar regardless of whether a patient has VHL. However, there is some evidence about specific VHL considerations regarding two types of treatment: surgery and targeted therapy. For a person with VHL and kidney cancer, surgery for a kidney tumor is generally considered when a tumor reaches three centimeters (cm) in size.

Targeted therapy is a treatment that targets the cancer’s specific genes, proteins, or the tissue environment that contributes to cancer growth and survival. Anti-angiogenesis therapy is a type of targeted therapy used in kidney cancer treatment. It is focused on stopping angiogenesis, which is the process of making new blood vessels. Because a tumor needs the nutrients delivered by blood vessels to grow and spread, the goal of anti-angiogenesis therapies is to “starve” the tumor. For people with VHL, there is emerging research showing that an anti-angiogenic drug called sunitinib (Sutent), which is classified as a tyrosine kinase inhibitor (TKI), may be effective against kidney cancer. Learn more about this approach in the general Kidney Cancer Treatment Options section of this website.
What are the screening options for VHL?

It is important to discuss with your doctor the following screening options, as each individual is different:

Yearly eye examination to look for retinal tumors, beginning around age 2

Yearly physical examination

Yearly 24-hour urine test to screen for elevated catecholamines, beginning around age 2

Yearly abdominal ultrasound (which uses sound waves to create a picture of the internal organs) to look at the kidneys, pancreas, and adrenal glands beginning in the teenage years; change screening to abdominal computed tomography (CT or CAT; creates a three-dimensional picture of the inside of the body with an x-ray machine) scan in adulthood

Magnetic resonance imaging (MRI; uses magnetic fields, not x-rays, to produce detailed images of the body) of the brain and spine every two years beginning in the teenage years

For more detailed screening recommendations by age group, see the National Cancer Institute screening protocol for VHL at www.vhl.org/meetings/meet98/efglen.htm.

Screening options may change over time as new technologies are developed and more is learned about VHL. It is important to talk with your doctor about appropriate screening tests.

Patient organizations for help and support of people with kidney cancer

IKCC (International Kidney Cancer Coalition)

IKCC is an independent and democratic network of patient support and advocacy organizations established with the mission of improving the quality of life of patients and their families living with kidney cancer. IKCC provides information, support and assistance to national kidney cancer organizations.

Organization in the world:

IKCC - http://www.ikcc.org/
Kidney Health Australia – Australia- www.kidney.org.au
Instituto Oncoguia – Brazil – www.oncoguia.org.br
Kidney Cancer Canada – Canada – www.kidneycancercanada.ca
Shanghai Roots and Shoots – China – www.jgi-shanghai.org
Association for the Finnish Cancer Patients – Finland – www.cancer.fi
Juliet Ibrahim Foundation – Ghana - www.julietibrahimfoundation.org
VHL Family Alliance Affiliate in Greece – Greece – www.vhlgr.blogspot.gr
Hungarian League Against Cancer – Hungary – www.rakliga.hu
V Care Foundation – India – www.vcarecancer.org
Kosovo Association for Cancer Care (KACC) – Kosovo
VHL Netherlands – Netherlands – www.vonhippellindau.nl
Association „Gladiator“ – Poland – www.gladiator-prostata.pl
Cancer Association of South Africa – South Africa – www.cansa.org.ua
Patients organizations in developed democracy countries perform several functions, namely: they express and protect interests of patients, members of the community who joined the organization of the Patient Protection and continuously monitor the state authorities to carry out their main tasks for the interest of patients. It is particularly important to note that these organizations are independent of public funds and therefore have the opportunity to be independent and in their work.

In Canada, public organizations are almost 100 years and are approved by law. In the U.S., civil society organizations are supported by the state budget. The budget of the Ministry of Health of the U.S. 30 % of laid on a tender basis to perform certain tasks, such as public awareness, raising some issues in society. On the one hand, they serve as the part of the Ministry of Health, on the other - Ministry operates transparently and openly, with public participation in decision-making.

NGOs represent a particular community; they are manifestations of public opinion for some problems or issues. Association of patients expresses opinion of sufficiently large number of patients. So the point of view of patients and physicians will be taken into account when making strategic decisions and solve current issues. Of course, doctors and patients will receive the documents in which they are developing through representatives of associations directly involved. Thus, on the one hand, the state receives protection and assurance that the interests of the public to some extent taken into account, on the other - protecting patients receive as they have an opportunity to share their views on a particular issue.

The important role of kidney cancer organizations lays on educational activities on the issues connected to prevention, symptoms, diagnosis and treatment of kidney cancer. During the IKCC Conference, the audience was informed of the national campaign against kidney cancer in the UK, Netherlands, USA, Uganda and others. These campaigns are mostly oriented to prevention and early diagnosis of the disease with the objective of informing the public about early signs of kidney cancer, the importance of timely visits to the doctor (video, leaflets, TV- programs, social networks etc.).
Dr. Ann Merimen told the story of creation of her first hospice for cancer patients in Uganda and achieving of free propagation of anesthetics for the population of country. Currently for these important activities Dr. Merimen is nominated for the Nobel Peace Prize.
Volunteer movement

It is flattering to recognize that today all over the world, including Ukraine, the process of revival of human values and humanization of society, is going on. The appearance of the modern volunteer movement is one of the ways of humanizing our society. This movement plays an important role in the implementation of any social projects. But of course, like any activity, social activity of volunteers has its own specific features.

Some features that allow a clear distinction between two types of volunteers:

1. **Volunteer who works for a long time.** The first type is most appropriate volunteer according to traditional idea when we hear the word "volunteer". Volunteers who work for a long time, consistent with the general notion of a volunteering and who has devoted itself to a particular case or group. He has such features as full impact to activities of an organization, strong motivation to volunteer work and to achieve the most successful outcome.

Many of the formed organizations rely on these volunteers working for a long time, creating jobs that require constant time for a longer period. In many cases, this type of volunteers are the real creators of
the organization for which they work, helping to find structure in which they will work themselves later.

Traditionally, these volunteers are housewives with average and good incomes who have free time and can always spend some of time finding their goal of life, or considering it as equivalent to a successful career. Many people from among the unemployed, pensioners and people with low incomes devote their time long-term projects.

2. Volunteer who works for a short time. Over the last decade different types of volunteering have begun to develop. One kind is the one that can be called as a "volunteer who has a small amount of time". He is characterized by the following features:

1. He can join the organization because he is able to conduct some work necessary for the organization and of interest for the volunteer. The organization not necessarily will have this person for the job.

2. He can be involved in participation of an event of interest or social events held by the organization.

3. Moreover, he can be attracted by the "forced choice" that is "invited " to a friend volunteer work. Usually, these people have only personal connection with those who have invited them, but not because of the importance of understanding the general case.

Another type (style) of a group of volunteers - volunteers who are involved in the particular event – these are the volunteers who come to participate in a particular situation or a short event that happens to a person, group, organization or society. These volunteers may be related to the organization of volunteer work only on the day of the event.

Management of volunteering: the most important in the work of volunteers, of course - is awareness of the need of their own activities and the availability of working. The main advantage of the volunteers is that they perform a job that they like and enjoy, when they see the results. But people feel this way only if they know that they are appreciated and recognized. Volunteers need belonging, recognition, and in some cases - an impact. People are working harder and more willing to do the work if they are given more room for creativity, responsibility, development of personal skills and talents. The most significant reason that volunteers work in organizations is a sense of belonging and contribution. Interest and efforts stem from the meaning ownership and common goals, participatory planning, clarity of expectations, responsibilities, progress and confidence that will provide adequate head support and recognition.

Therefore, importance of the following aspects of management of volunteers as strategic planning, individual management, participation of volunteers in the organization and management of information are increasing all the time.

However, individual volunteer management remains important, elements of which is to determine the purpose of the volunteer project, the involvement of volunteers, their selection, assistance in adjusting to the duties that meet the motivational needs and goals of the organization, providing support, encouragement and training.

The most important aspects of the management of individual volunteers and its main elements and steps is to attract and selection of volunteers, their training and supervision, support and encouragement.
Training volunteers to form the necessary skills (psychological, medical etc.). It can be individual or collective nature. For teenagers, students, volunteers, parents it can be theoretical and practical courses.

From training of volunteers a large part of the success of the program depends in the future. It is important to prepare volunteers not only professionally, but also morally, especially when the latter has to work with the families of disabled children, hard disease patients, homeless families, prisoners.

In Ukraine volunteering becomes increasingly popular as in other countries, and we are pleased that the number of volunteers is growing every year.

This shows that people want to make their own, albeit small, but still contribute to maintaining and improving the lives of others.
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