

HPV STORIES



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When we began working on establishing the Forum for the Elimination of HPV, we had one idea in mind – to make patients' voices the foundation of our activities. Behind every statistic, every vaccination rate, and every incidence rate, there are real people. It is their lives, their everyday experiences, their fears, and their hopes.

“HPV Stories” is a unique project that gives voice to those who have experienced the consequences of HPV infection. Thanks to the courage of the protagonists – Aga, Asia, Karola, Agata, Kasia, and Tomek – we can look at the problem not through the prism of medical concepts, but through human experiences.

These are stories that teach humility, but also inspire and give hope. The photographs by Dorota Szulc and the stories written by journalists create a record not only of the disease, but also of the struggle for each new day, for normality and dignity. It is also proof of the strength of community – the support of families, friends, doctors, and patient organizations, which, step by step, are changing the system and public awareness.

Personally, I believe that such testimonies have more power than many reports. Although reports indicate our goals and show the scale of the challenges, it is human stories that touch our hearts, stir our emotions, and motivate us to act. Eliminating HPV-related diseases is a challenge that we can only take on together – through education, vaccination, testing, and courageous conversations.

I hope that this album will inspire reflection and encourage people to make or reconsider informed decisions – both individual ones concerning their own health and systemic ones that institutions and decision-makers face on a daily basis.

I would like to thank all the protagonists for their courage and trust. I would like to thank the photographer, journalists, and partners of this project, but above all, I would like to thank everyone who takes the time to pick up this album, because I believe that every encounter with another person's story brings us closer to a future in which HPV will no longer be a threat.

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ANDRZEJ NOWAKOWSKI, MD, PHD
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For years, I have been involved in the early detection, diagnosis, and treatment of cancers caused by HPV, and I know that behind every case there is a human tragedy affecting the patient and their family. Cervical cancer, as well as other HPV-related cancers, continue to rob too many of the cervix, but also other HPV-related cancers, continue to rob too many women and men of their health and lives – even though we have effective tools at our disposal to prevent this.

This album is extremely valuable because it shows human faces and emotions that no statistics can convey. These are testimonies of courage and determination, but also a warning and an appeal for wise decisions. HPV prevention – vaccinations, screening tests, i.e., HPV tests and cytology – is a real opportunity to eliminate these diseases.

As a doctor, I believe that through education and the promotion of prevention, we can ensure that future generations will be free from cervical cancer and other HPV-related cancers.

The stories of the patients presented in this album are a powerful voice in this matter. It is a voice that we should listen to – and respond to with action.



Patient: Agnieszka Blanka Snarska | Author: Agnieszka Szttyler-Turovsky

I WALKED INTO WORK AND SAID: “I HAVE CANCER.”

They were in Rome. Piotr ran a marathon. Time: three hours and fourteen minutes. A personal best. They sat down in the park.

He took out a ring and proposed. And she said, “But you know I could die, right?” “I ruined the romantic moment a little,” recalls Agnieszka Blanka Snarska. Today they are married.

After her illness, Agnieszka became a psycho-oncologist. Autumn 2021. A day like any other. Agnieszka, a specialist in EU funds, works for a state-owned company. She is sitting at her desk, in front of her computer. Her cell phone rings. The display shows a call from Ania. She is a friend, a gynecologist. Agnieszka guesses that she is probably calling with the results. She has been waiting for this news for three weeks — that’s how long it’s been since her Pap smear. With each passing day, she becomes more and more impatient, although theoretically she has nothing to fear — she has this test done regularly, every two years. She goes out into the hallway with her phone. “I have cancer, I just found out.” „Agnieszka... it took so long because... cancer cells were detected. Don’t worry prematurely. We’ll do in-depth diagnostics. We’ll treat you,” she hears. „In an instant, my whole world stops. It ends. Diagnosis: cervical cancer. Shock,” she recalls. She had always been emotional. Now, in this hallway, she remains calm. She talks to Ania about the next steps - tests, hospital. Poker

face. No one can tell what just happened to her. „I didn't even cry,” she recalls. She ends the conversation with her friend. She returns to the open-plan office.

She immediately blurts out: “I have cancer. I just found out.” „People got up from their desks and started approaching me. They tried to comfort me. They hugged me,” she says. At 5 p.m., Agnieszka leaves work. People react to stress in different ways. She freezes.

She acts calmly, step by step, performing one task after another. “I go into emergency mode,” she says. That's how it is right now. Straight from work, she goes to the subway station. She gets on. She gets off at the Natolin station. She heads straight to the apartment of Piotr, her boyfriend. From the doorway, she tells him what happened. Piotr hugs her. He makes Agnieszka some sandwiches. That evening, we didn't dwell on the subject of cancer. Especially since we didn't really know how serious the situation was, recalls Agnieszka.

She had never been seriously ill before. She didn't even get colds. She has a Pap smear every two years. This one was also routine, during a visit to the gynecologist. „I had no symptoms of the disease developing inside me,” she recalls. “Cervical cancer doesn't show any symptoms for a long time,” she adds. At that time, Piotr was finalizing the purchase of an apartment. Two days later, he took Agnieszka to the notary. We got caught up in other topics. There was no talk of illness,” she adds.

Piotr has been a solid support for her since that first evening.

„There was no crying or breaking down. He distracted me so that my thoughts didn't revolve around cancer,” she recalls. He, like her, just acts. „There was no crying together, no breaking down. He distracted my thoughts so that they didn't revolve around cancer,” she recalls. He, like her, just acts. Every day of waiting for the biopsy results is an eternity. She wasn't interested in oncology before her diagnosis. Her associations with cancer were: “Difficult treatment, chemotherapy, hair loss, and death.” But when she heard the diagnosis, she wasn't afraid of death at all.

The thought that I would die never crossed my mind. What was overwhelming was the feeling that I had let my body down.

Agnieszka – I felt totally disappointed that my immune system had failed me.

“And if that's the case, what else will my body do to me?” I wondered, she recalls. Then the agonizing thought came: “The cancer has metastasized.” Where do I have metastases? „Do

I have cancer everywhere, or just locally?” I tormented myself. „I was most afraid that they were in my brain. Maybe because the brain is a sense of control, of self-determination? I was afraid that I would lose it if something bigger than me took control of me,” she recalls. I didn’t know

then that cervical cancer doesn’t metastasize to the brain,” she says. That’s why this thought, like an obsession, tormented her for the next three weeks. That’s how long she had to wait to find out what stage the cancer was at. „The worst thing about having cancer is the waiting. The fact that you have to wait so long is downright inhumane,” she says. It’s three weeks every time.

“There’s no way around it — there’s a shortage of histopathologists in Poland,” she explains. But there are countries where a woman knows the results of her biopsy after just a few days. “And every day is an eternity,” she says. When someone asks her what it’s like to have cancer, she replies, „Being sick is an eternal wait.” For tests, for results, for checkups... With many diseases, you have to wait. That’s a given. “But there’s a huge difference between waiting with your leg in a cast for it to heal and waiting for biopsy results,” she says. She would like doctors to have more time for their patients. „It’s not easy to have to give someone a diagnosis with different prognoses every 15 minutes,” she says.

She also dreams that HPV tests will finally be free for everyone. And liquid cytology. „I’ve seen too many patients who had regular cytology tests — the traditional ones. The results came back fine, and that lulled them into a false sense of security. They got cancer,” she says.

Netflix distracted her from thinking about her illness

That fall and winter—2021—Agnieszka waited and went to work every day. She didn’t take any vacation or sick leave. There were days when it was difficult to get out of bed. Sometimes she comes to work an hour or an hour and a half late. She has the support of her team. And her boss. She tells him that coming in is pointless: „Listen, I’m not doing anything anyway, I’m just thinking about what will happen to me next,” and he says, “It doesn’t matter. Just come in.” After work, Agnieszka tries hard to keep herself busy with anything so she doesn’t think about her illness. Piotr helps her. „We watched a lot of Netflix back then. Mainly documentaries about successful restaurants and their inspiring chefs. I don’t remember almost anything from them, I couldn’t concentrate at all,” she says.

She has a friend who has had cancer. „Now is the worst. You’ll see, once the treatment



starts, it will get better," she kept telling me at the time. She was right," says Agnieszka.

She goes to the oncologist with her boyfriend and a list of questions.

Hospital. First visit. And the second. Taking more samples. The fate of further treatment hangs in the balance. It is not entirely clear how much of her body the cancer has taken over. Surgery under short-term anesthesia. Agnieszka is not afraid. The night before the surgery, she does not torment herself with dark thoughts. Rather, she feels relief — sleep is an escape into a world without illness — she recalls. She has to make the decision herself about what kind of fertility-sparing treatment to choose. It's a choice between getting pregnant and having a baby or not. Because a hysterectomy is the removal of the uterus. Her friend, a gynecologist, says: „Agnieszka, we can do it this way: you get pregnant, carry the baby to term, give birth. Only then will we do the surgery.“ ”I couldn't imagine walking around with cancer for nine months. Ania kept repeating to me, just in case: “You know this is an irreversible decision, right?”

I didn't want to tempt fate. I preferred to save my life," recalls Aga. A friend recommends an oncologist to her. She goes to see Prof. Grzegorz Panek with Piotr. She also has a piece of paper with her with a list of questions. Just as the girls on Facebook forums advised. „They said to go with someone or even record the conversation with the doctor, because when you're stressed, you always forget something," recalls Agnieszka. At the appointment, she reads the questions from the list. There is no question about her prognosis. But there are questions such as: “Can I drink coffee?” The doctor says yes. On the forums, people write that “cancer feeds on sugar,” so she also asks, “Can I eat sweets?” The doctor says yes. Agnieszka has her surgery at a hospital in Warsaw. It is December 5, 2021. Two months after her diagnosis.

Living in uncertainty, she isn't even planning New Year's Eve

They spend Christmas with Piotr at his parents' house. Agnieszka is only 19 days after surgery. They travel from Warsaw to Białystok. „I didn't have to stay in bed for long. You get up the day after the operation. I left the hospital after three days. My boyfriend's help was very useful — I couldn't bend over, I couldn't carry anything. I was very weak. I remember that Piotr made me a lot of fresh juices at the time," recalls Agnieszka. She is recovering quickly.

“I sat at the Christmas Eve table wearing makeup and elegant clothes," she recalls.

Unfortunately, the histopathology results from the surgery are not yet available. She is waiting again.

One of her friends asks what they are doing on New Year's Eve. She is not making any plans for the future. Even though that "future" is only a few days away. „You don't die of cancer overnight, but in those days I couldn't even imagine the next day," she recalls.

It will be as she wanted — no chemotherapy

December 27, 2021, 9 a.m. Another call from Ania catches her at work. This time during a conference. Agnieszka goes out into the hallway with her cell phone.

"Everything is OK. It's at an early stage. And just as you'd hoped— no chemotherapy," she hears.

Agnieszka repeats to herself: "I'm healthy!" "It was a milestone. I felt like I was in heaven," she recalls. She is glad that she will not need chemotherapy. She had been most afraid of that. Much more than surgery. „At that time, I didn't know that after the chemotherapy you get for cervical cancer, you don't even lose your hair," she says. She hears that she is healthy, and only then does depression hit her. It is January 2022.

"Theoretically, I should have been happy. But I wasn't. I still had to get used to the thought that I was healthy, as if I couldn't believe it," she recalls. Instead of relief and joy, she feels depressed. Only now does she break down mentally.

"I felt really bad," she recalls. People around her don't understand. "Look, it's behind you. You've had the surgery. You're in remission. You're healthy. You should be happy." "I felt really bad," she recalls. People around her don't understand. „Look, it's behind you now. You've had the surgery. You're cured!" they repeat. But she can't be happy. She doesn't understand what's going on.

„I went to a psychologist then. For a free appointment at some foundation. She helped me a lot at the time," says Agnieszka. The psychologist tells her that what she is feeling is normal. This is not the time for joy. After all, for over three months, Agnieszka has been on the brink of death. Everything happens at a rapid pace — hospital, biopsies, operations, IVs. And suddenly it stops. Just like that, from one day to the next. — in a life-threatening situation. Everything is happening at a rapid pace — hospital, biopsies, operations, IVs. And then suddenly it stops. Just like that, from one day to the next, she is supposed to trust that nothing bad is happening



anymore? Her head can't keep up. In such moments, help is very important, not only from a psycho-oncologist. Also a psychiatrist. Because depression and anxiety are very common. During the illness or only after it. Pharmacotherapy can help a lot, says Agnieszka.

She used it herself.

She sought support in a Facebook group, now she gives it to others

March, 2022. Rome. Less than six months after the diagnosis. Piotr runs a marathon. Aga cheers him on. His time: sensational. Three hours and fourteen minutes. A personal best! After the race, they go to the park. They sit on a bench. He starts talking about how he wants to spend his whole life with her. He takes out a ring... "But you know I could die!" I replied. I kind of ruined the romantic situation," she recalls. She did, but only a little. They get married a year later, on March 31, 2022. In the Dominican Republic. Seven months after the operation, she starts a Facebook group.

Before that, she was in two herself. She approached girls on forums and wrote to them privately: "Hey, how was your treatment? Where were you treated? By whom?" She established new relationships, and at one point was corresponding with 30 women.

But the groups she joins are a total mishmash - women with ovarian cancer, uterine cancer, cervical cancer. Agnieszka sees that a forum for girls with the latter diagnosis would be useful. That's when she starts her own: "Cervical cancer support group for women with a diagnosis."

Today, there are 700 women on it.. The group features information verified by experts. There are no "magic" therapies or suspicious fundraisers. There are no taboo topics.

The girls talk about everything: treatment, complications, and how to deal with them — for example, with a bladder after radiotherapy. They also talk about hormone replacement therapy, because women who have had their uterus and ovaries removed, even if they are only thirty years old, have gone through menopause overnight. There are questions about the formalities of applying for benefits, but also about whether it is possible to dye your hair and have sex after surgery. The girls also post their test results here, especially PET scans, to share the happy news that the PET is "clean," meaning there are no metastases. "At times like these, we all rejoice together," says Agnieszka. Only now the roles have reversed a bit — she used to seek support from the group, but now she mainly gives it to others. She has just become a psycho-oncologist. She graduated with honors from SWPS University .She

started her own business and also works as a psycho-oncologist at the Onkocafe-Razem Lepiej Foundation. “I got really into it,” she says. She helps patients navigate the entire process, from diagnosis through the entire disease and its treatment. Not only patients, but also their loved ones.

“Cancer turns the lives of entire families upside down,” she points out. My style is humorous and coaching-oriented,” she says. This is useful, for example, when someone is mentally broken but still hesitates to see a psychiatrist. „Then I say, ‚What are you waiting for? You have cancer, if not now, then when?!’ „ It works. Today, she enjoys every day. She has become involved in gardening. She buys flowers — annuals, so every winter she waits for spring to plant them again and tend to her garden. It’s English-style — lots of colorful flowers and shrubs. Hydrangeas, grapes. „My husband and I love to drink coffee in the garden, in the full sun,” she says. When she and Piotr met, he had a dog and she had two cats. „They were also a source of support for me during my illness, at the beginning, when Piotr and I weren’t living together yet. The touch of the cats, their warmth, and the fact that I could care for them gave me comfort,” she recalls. Now the cats and the dog run around the garden together. They live in harmony, not at all “like cats and dogs.” “It wasn’t easy at first. And it took a few behaviorists,” laughs Agnieszka.

Today, it’s been over three years since her treatment. She divides her life into before and after. „Back then, I couldn’t Today, I’m already planning, although still only up to six months ahead,” she says. Those six months are no coincidence — that’s how long it takes to get the next test results. When she waits for the results, even though she is already healthy, she is sometimes even more afraid. „Today I have more to lose. Now I have a great life — even better than before the illness — back then, after the diagnosis, I was at rock bottom,” she says. When fear overwhelms her, she sticks to the facts. What the results and the doctor say — that she is healthy. She emphasizes: „However, I haven’t forgotten about the illness. It’s impossible to forget. Although it’s still in the back of my mind, today I draw on this experience — I don’t put my life on hold, I don’t worry about things I can’t control. I choose kindness. I enjoy life every day. Precisely because I know how fragile it is...

”I am not alone



Patient: Agata Jóźwiak | Author: Bożena Stasiak

I DON'T KNOW ANY OTHER LIFE.

She has just returned from the hospital after another ENT procedure. One of several, dozens? “I can’t count them, I don’t know, but there were definitely over... 100!” replies

Ms. Agata in a whisper, as speaking will still be very difficult for her for a few more days.

How long the effects of this procedure will last is also impossible to predict, but judging

by the procedures she has undergone so far, it will certainly not be for long. Sometimes it was better, sometimes worse, but recently it has been worse, she is recovering more slowly, as if her immune system were already giving up.

Ms. Agata has suffered from a rare, chronic disease since birth — recurrent respiratory papillomatosis (RRP).

„I was born with this condition. I was delivered naturally, and most likely that’s when the infection occurred. I learned much, much later that this could have been the case, that this could have been how I became infected with the human papillomavirus (HPV), specifically one of its non-oncogenic types, 6 or 11.

I remember my childhood and later years mainly from my stays in the hospital. I had my

first surgery when I was about 5 years old. From family stories, I know that my parents were concerned about my hoarseness, shortness of breath, and breathing problems, which appeared independently of colds.

Fortunately, my parents found a good ENT specialist, Dr. Krawczyński, who immediately referred us to a children's hospital in Łódź, where we lived and where I still live. He took wonderful care of me for many years. The treatment for this disease consisted of mechanically removing the papillomatous lesions, which kept growing back. Sometimes I had to undergo such operations. Treatment for this disease consisted of the mechanical removal of papillomatous lesions, which kept growing back. Sometimes I had to undergo such operations.

It is not difficult to imagine what this meant for a small child. And in those days, it was not the case that my mother sat next to me to cuddle and comfort me... Fortunately, the very good staff allowed us to at least partially forget about the discomfort associated with the disease and being away from our family. And we had normal, well, almost normal lessons, so we didn't fall behind our peers.

Agata finished elementary school without any problems, then high school. Despite the recurring papillomas, which mainly appeared in her throat and larynx, and despite frequent treatments, eventually performed using laser technology, she tried to function like everyone else. After high school, she continued her education at university. She chose geography.

„Now I am under the constant care of a professor from Poznań, where I go for treatment. I ended up in Poznań thanks to a recommendation from one of the doctors in Łódź. The doctors at the clinic in Poznań specialize, among other things, in conditions related to RRP. The doctors there who treat papillomas use the same treatment methods that are used in other medical facilities around the world. Patients with papillomas come here from all over Poland to be treated.

As far as my quality of life is concerned, I feel that it used to be better. This is because over the years, the condition of my upper respiratory tract has deteriorated significantly. The successive removal of papillomatous lesions has not been good for my larynx and my whole body. Adhesions and scars have formed in my larynx, and it has narrowed considerably, which has worsened my voice disorders. Even though I speak better a few days after the procedure, it is no longer a good, clear voice, because I will not regain it. It is true that there is a possible procedure involving widening the larynx by inserting a special strut, but it is very unpleasant



**"Hope grows
with me**



and risky, and the outcome is difficult to predict, so I don't think I will decide to undergo it .

On the other hand, when the shortness of breath and breathing problems get worse, I may have no choice...

- However, I still hope that some kind of therapy or medication will be developed that will prevent these papillomas from growing back almost immediately after removal, something that will stop them from developing altogether. After all, anything is possible in medicine, right? Anyway, apparently scientific research is already being conducted in this area.

On a daily basis, Agata tries not to overload her body, to live in harmony with it. She is a loner, she likes to return to her apartment, to the books she devours with passion. She likes solitary walks in the forest, where she can breathe easily. However, she is not entirely a loner, as she has a group of friends with whom she goes on quite long trips. The last one was planned to Arizona, but she had to undergo surgery and had to cancel the trip.

Unfortunately, the thought that she will have to undergo another procedure to remove lesions from her larynx is always "on her mind," and this usually happens at the least opportune moment.

When I think about what bothers me the most about my illness on a daily basis, what is most uncomfortable for me, I think that the most annoying thing is the fact that the papillomas keep growing back. This means that when I am planning, for example, a trip outside Poland, I have to take into account the date of the next procedure.

Another thing is that one day everything is fine, or so it seems, and the next day I wake up and feel that I already have a big problem with breathing and I have to quickly go to the clinic to schedule a procedure. Unfortunately, this is the case for most people with papillomas who have been struggling with this condition since childhood.

Well, for now, we have no choice but to learn to live with it and accept it. There's no point in getting angry, that's just how it is. I think that having struggled with this for many years, it's easier for me than for people who developed it later in life. I don't know any other life.

My day is the same as that of any other healthy person. I don't take any medication on a permanent basis. However, speech therapy exercises are recommended after surgery.

I would like there to be greater awareness of this disease and greater access to information about it.



Patient: Tomasz Kuropatwa | Author: Katarzyna Staszak

22 WEEKS WITH A NO TALKING RULE.

I can't say a word for two weeks after the procedure. The procedures have to be repeated regularly because the warts in the throat grow back regularly.

Katarzyna Staszak: You have had growths removed from your larynx 11 times already.

Tomasz Kuropatwa: Yes. I have papilloma caused by HPV. I am currently waiting for the date of my twelfth procedure. My doctors in Poznań call me a “spectacular patient.” I would prefer not to stand out like this, but I can't help it, it's my fate.

When did you first feel that you had a problem with your throat?

It started three and a half years ago. It was summer, and my voice remained hoarse for a long time. I felt as if something was bothering me in my throat, limiting my voice. I couldn't speak freely and it started to bother me. I went to my family doctor, who gave me a referral to a cardiologist. Hoarseness can be a sign of heart disease, hence the idea. The cardiologist examined me thoroughly and sent me back to my family doctor. I got another referral to an ENT specialist, who decided that I had to go to the hospital's ENT department. It was six months after my first visit to the clinic. I lost so much time waiting for further consultations with doctors. That's how it is in my small town. I decided to go to Poznań for treatment.

Here, the diagnosis was clear - papilloma caused by the HPV virus. I was referred for CO₂ laser treatment.

Did it hurt?

I had the procedure under general anesthesia, which meant I was unaware of what was happening. The challenge was the recovery. A liquid diet for a while, and then a complete ban on speaking for two weeks.

Two weeks times 11 procedures. That's 22 weeks without speaking. How did you cope with that?

The first time was the hardest, but it turned out that you can get used to not speaking. course, it's also a challenge for my loved ones and the people I work with. I'm a sales director. Before the procedure, I let everyone know that I'll be switching to email and texting. It's manageable.

How do you feel when those two weeks are over and you can use your voice again?

It's a great relief. I can speak freely again—with the ease I remember from before my illness.

You now speak with a slight audible hoarseness.

It's been almost three months since the last procedure. I'm waiting for the date of the next one. It may seem terrible, but I actually notice an improvement. I remember how I used to feel three months after the procedure. I spoke with greater difficulty, after 10 minutes of conversation I had to take a break to drink water. The hoarseness returned as soon as I started speaking after my recovery. I hope that the intervals between treatments will get longer and that the HPV will become less active.

This virus is commonly associated with cervical cancer in women. The fact that it is also dangerous for men became widely known thanks to the confessions of actor Michael Douglas. He revealed that he had oral cancer caused by HPV. In men, the virus can also cause penile and anal cancer. Douglas recently appeared in an HPV awareness campaign.

Doctors tell me that they see recurrent papillomas like mine in children.

They contract HPV from their mothers during childbirth. The regrowing warts make it difficult for them to eat. Some children have dozens of oral procedures. Didn't the prospect of constantly returning for procedures scare you?

Over a year ago, I had a slight crisis. I read on the internet that sometimes procedures have to be repeated several times, and I thought that would be enough for me too.

I turn "fear
into courage

Have doctors advised you to take care of your health?

I have to maintain a strong immune system. I started taking probiotics and thinking about whether I was getting enough vitamins. I eat regularly and healthily, and I make sure to include fruit. I used to eat fast food once every two or three months, but I don't do that anymore. I've realized that it's important to watch what I eat. I've found time for exercise—cycling and swimming. When you're 40 years old and hear about diseases, you think it doesn't apply to you. But illness can always take you by surprise. I don't know if I would have gotten sick if I had taken care of myself earlier. I know that now, apart from my throat problem, I feel better.

We have many opportunities to come into contact with HPV during our lifetime. Through sexual contact, but also through skin-to-skin contact. In most cases, the body fights off the virus, which is why it is important to take care of your immunity.

Before all this started, I used to catch a cold or the flu twice a year. Since I've been watching my diet, I don't catch colds at all. I'm motivated, I have to keep going with this treatment.

I hope that one of the procedures will be the last one.





Patient: Karolina Ślusarska | Author: Bożena Stasiak

AFTER 30 DAYS, THE RESULTS CAME BACK AND - SHOCK !

When she went for a check-up in May 2021 at the private clinic she had been attending previously, the doctor performed a Pap smear as a preventive measure. The result was very good, as was the assessment of her reproductive organs. The results were so good that the doctor did not see the need for more in-depth diagnostics. Imagine her surprise when, less than a year later, in March 2022, she began to experience bleeding from her reproductive tract, something that had never happened to her before.

“And then the problems started, which I didn't expect at all, because how could I, since the previous tests indicated that I shouldn't have them,” says Karolina. “Of course, I went to the doctor, first to one, then to another and then to another, because each of them tried different ways to stop the bleeding instead of looking for the cause right away. That's what I resent about doctors, including the one who took my Pap smears. Because now I know that it should have been a liquid Pap smear, not a traditional one. Then it would have been clear that what was happening in my body was serious, not just bleeding that could be stopped and then investigated.

In July, I went to the hospital on Kamieński Street, but I was not admitted there. One of the employees told me that they “did not have enough staff” and advised me to arrange for the biopsy to be taken privately. It cost about PLN 2,000. On the same day, I went to the hospital in Oleśnica, where I was taken care of, various tests were performed, and the biopsies were taken the next day.

After 30 days, the results came back and — shock! Cervical cancer, with infiltrations, which meant that surgery was no longer an option.

Of course, I asked how it was possible that I had cervical cancer, and that it was already inoperable, when the cytology results were so good... Another doctor who diagnosed me said that this cancer must have been developing for some time. And yet I regularly went for checkups, spending a lot of money in private clinics... So it wasn't me who must have overlooked it...

After receiving the biopsy results, things moved quickly. Karolina was given a DILO card, underwent a CT scan, an MRI, and received a treatment plan at the Lower Silesian Oncology Center Oncology Center in Wrocław. However, before therapy could begin, another transfusion was necessary due to very low hemoglobin levels. Only after a few days, when the results improved, was it possible to proceed with the treatment plan.

“But not everything went according to plan,” recalls Karolina. “I received 50 radiation treatments and was supposed to receive 6 chemotherapy treatments, but after just two I felt so terrible, my results plummeted, and further chemotherapy had to be abandoned because it could have killed me. And then there were four brachytherapy treatments.

The chemotherapy was terrible. For the first few days, I had all the possible side effects, and I was so weak that I couldn't get out of bed at all. The radiation therapy, on the other hand, was almost “painless.”

She spent a total of 2.5 months in the hospital. When she had to give up chemotherapy, she was put on steroids. And this treatment proved to be effective. So much so that in September 2024, she was able to return to work, to her previous position as purchasing coordinator at a catering company, where she was given an extremely warm welcome.





Now, when I look back on my illness, it may seem that despite the initial problems, it wasn't so traumatic. But I had moments of breakdown, I cried, which is probably normal in such situations. My biggest support from the very beginning was my sister, for which I am extremely grateful. And people I met along the way.

The psychologist and psychiatrist who encouraged me while I was still in the hospital. During my therapy, I met many nice people on Facebook, especially Agnieszka, who started a Facebook group for women with cervical cancer. After some time, she started looking for someone to help her with her administrative duties - and that's how I became a co-administrator of the group, which provides support and where you can find a lot of valuable

information about the treatment of this disease and life after treatment. We also have experts from various fields who work with us.

Like many cancer patients, I asked myself and my doctors where this cancer could have come from. I read a lot about it myself. There were no cases of cancer in my family, except for my dad, who had lung cancer and died at the age of 58, but he smoked a lot. The psychologist suggested that in my case it could have come from some unresolved trauma, from stress. It's true that I don't remember anything specific, but I always cared a lot about everything, maybe too much, I split hairs, I analyzed everything too much, probably not always logically. But that's in the past, I've put it behind me.

Now I try to live life to the fullest and do what I enjoy. I think positively, because that kind of thinking is extremely valuable. I eat healthily, I'm physically active, I regularly check my health, and I follow all my doctors' recommendations. I am currently waiting for the results of a follow-up MRI, which I expect to be good. And, speaking of physical activity, I have discovered a new passion — I have started training aerial acrobatics with a scarf and a hoop. This is partly due to the influence of my daughters, who are involved in this. I'm even quite successful at it, and I currently have a coach in this field. And maybe my next passion will be making beaded jewelry, which I was encouraged to try by the mother of one of my daughter's friends.

Today I know that HPV vaccinations protect against cervical cancer, but I didn't know anything about it before. And as soon as I found out, I had my daughters vaccinated immediately. I didn't even think twice about it. I believe that it will protect them from getting sick in the future. I will be calm. By the way, I plan to talk to my doctor, because maybe I can still get vaccinated too? It's true that these are vaccinations for teenagers before they become sexually active, but I read somewhere that at a later age, and even after cervical cancer, they can be important and protect against recurrence. I think that not enough is said about this. I have the impression that even doctors themselves do not promote these vaccinations.



Patient: Katarzyna Goj | Author: Anna Kaczmarek

I GOT INFECTED MOST LIKELY DURING CHILD BIRTH.

When I turned one, my parents noticed that I was losing my voice, I started crying more quietly, and I had a chronic cough. The symptoms were getting worse. Then I started having difficulty breathing during exertion, and later even when resting. Parents took me from doctor to doctor. It was over 40 years ago, and medicine was at a different level back then. The doctors diagnosed colds, laryngitis, and other diseases. Unfortunately, treatment aimed at these diseases was ineffective. It was difficult to make an accurate diagnosis. No one knew what was wrong with me.

The turning point came when I was referred to an elderly professor in Poznań who was collaborating with foreign medical centers at the time. From Rybnik, where I lived, I was transported by helicopter to a hospital in Poznań. The professor made an accurate diagnosis. He knew that there was such a thing as laryngeal papillomatosis. Unfortunately, the disease was so advanced at that point that the doctors had to perform a tracheotomy. After the lesions healed, my tracheostomy tube was removed. However, from that moment on, my life became a series of operations. It continues to this day.

The correct diagnosis was made when I was 3 years old. At that time, respiratory

papillomatosis was an unknown disease in Poland, which is why it took so long from the onset of symptoms to diagnosis, and the disease had made irreversible progress. That is why a tracheotomy was necessary. The disease had an impact on my education. I had to give up on many fields of study that interested me. All because of speech problems and frequent surgeries, which resulted in absences. It also affected my career path. Despite my higher education, I cannot work everywhere. The people I have to call or who call me have no idea that I am ill. I experience enormous stress when I have to call someone. People ask me to speak louder, they ask why I speak so quietly, if I'm okay. I try to do most things in person or in writing. I avoid using the phone.

The disease has also affected my personal and family life.

I have two children. However, pregnancy is risky because no one knows how it might affect the progression of the disease. With my first child, I was in remission for over a year, but during my second pregnancy, I had to have two surgeries. The disease affects my entire life, every aspect of it.

I got through my teenage years without any major problems. I was taught at home that everything was fine with me and that I was no different. I think that this instilled positive attitude helped me a lot.

However, I know that people suffering from the same condition as me have problems making friends and finding love. I did not experience this. I always had a group of good acquaintances and friends. Of course, I remember being teased at school. They laughed at me just like they laughed at my friends who wore glasses. I didn't care too much about it, but I think that was because of what I learned at home. During my life, I have undergone over 40 surgeries to remove lesions in my respiratory system. Sometimes these operations were performed every three weeks. The appearance of lesions depends, among other things, on what is happening in our lives. If I am nervous, my body's immunity drops, and these lesions grow faster, requiring more frequent surgeries. There are also periods when surgeries are needed less often, but there has never been a year when I didn't need at least one. I had the longest remission during my first pregnancy. My children are healthy. There are no studies that would indicate that papillomas located in the respiratory tract can be transmitted to children during pregnancy or childbirth. However, if such changes are present on the reproductive organs, then unfortunately the child can become infected.

Where did I get this disease? Today, I am not sure, but most likely my mother had lesions resulting from HPV infection in her reproductive tract. I most likely became infected during childbirth. Respiratory papillomatosis is not only a matter of the growth of lesions caused by HPV and the need to remove them. It also poses a risk of developing cancer.

Sometimes I wonder where I would be today if it weren't for the disease. How my life would have turned out.

**” My body,
my strength**





Patient: Joanna Biegaj | Author: Katarzyna Staszak

I DIDN'T HAVE TO GET Sick.

I started treatment with a fighting spirit, but it was so grueling that at the end I wanted to give up. After therapy, I couldn't imagine my future.

The treatment was devastating, but effective. I experienced terrible pain and a sea of tears. Those five months changed my life.

Katarzyna Staszak: You recently turned thirty. A lot has changed since your last birthday.

Joanna Biegaj: On my 29th birthday, I went to the hospital for a cervical biopsy. And more than two weeks later, I stood at the door of the doctor's office and waited to discuss the results. No one would call me in for a consultation about test results if they wanted to congratulate me on my health. I was nervous. The door opened, the doctor invited me into the office and told me that I was sick, that I had cervical cancer.

Was she sure about this diagnosis?

Yes. She looked at the biopsy results.

Did you feel ill at the time?

No. About six weeks earlier, I went to the gynecologist because I noticed that I was bleeding after intercourse. I was concerned, so I made an appointment for the next day. At the time, I didn't think about cancer. I felt healthy, I was living life to the fullest, I was working a lot. A year earlier, I had a Pap smear and everything was fine. The gynecologist examined me, did an ultrasound, found no obvious cause for the bleeding, but advised me to have a Pap smear. So I had a liquid-based Pap smear. After about a month, I found out that I was infected with HPV. At that point, I thought that maybe I had had the virus before, but my previous Pap smear had been done using the traditional method, which is not as sensitive.

Did the virus detected in the cytology test mean that you had to undergo a biopsy?

Yes. I didn't even have to wait for a biopsy appointment because someone from the hospital where I had the cytology test taken care of me. The midwife saw the results of the test and tried to call me on the morning of my 29th birthday. She kept trying because she wanted me to come to the hospital that day. On that particular day, the doctor who performed biopsies was available. She couldn't tell me the results of my Pap smear over the phone, but she asked, insisted, that I come quickly. Now I am very grateful to her for that. She was a midwife who was very committed to her work.

She was a dedicated midwife.

Yes, she fought to get me a biopsy as soon as possible. She couldn't tell me everything directly, so I was irritated by her insistence. I asked why I had to come right away. Finally, the midwife said that the cytology results were bad. Within an hour, I was at the hospital. And three weeks later, I learned the diagnosis.

Did you consider such a diagnosis while waiting for the biopsy results?

Not really. During the procedure, the doctor and midwife reassured me that it was a control measure. That it was necessary to check that everything was okay. The midwife was a wonderfully empathetic person. During the biopsy, she held my hand, stroked me, apologized for the pain, and told me I was too young. I understood that it was a way of conjuring up reality: I was too young for it to turn out to be cancer.





Was the tissue sampling for histopathological examination an unpleasant experience?

I didn't know what a cervical biopsy should look like. There was no anesthesia, so it was terribly painful for me. And I have a high pain threshold. I remember when I left the office, my blouse was all wet with sweat.

Medical descriptions of the procedure say that local anesthesia should be used.

Intuitively, I felt that way, but I didn't ask about it. At the time, it wasn't important to me. I was emotional, scared, and all I knew was that the biopsy had to be done quickly.

Later, I told the nice midwife that I only got through it thanks to her. Thanks to the fact that she held my hand and supported me. I know now that it shouldn't be like that, but in all this, I also got a lot of support from that midwife.

After three weeks, I called the hospital to ask if the biopsy results were in. They were, and I was to find out on Wednesday during a consultation. I didn't wait until Wednesday. I went to the hospital straight away.

The test results were given out that day by the midwife who had been so nice to me. She told me to wait in the hallway outside the doctor's office. I waited a long time, and the midwife was busy with other patients. I thought she was ignoring me, other women were getting their results, and I wasn't. Later it turned out that she wanted the doctor to tell me the news about the cancer. She didn't want me to look in the envelope myself. I remember that the doctor very calmly and directly told me that I had cancer. My twin sister was with me in the doctor's office.

How did you react?

Strangely enough, calmly. I started asking a lot of questions—about how advanced the disease was and what my treatment options were. The doctor said she needed to examine me and that was why my mother had made the appointment. So I went back to see her on Wednesday. All this happened at the municipal hospital, run by the city of Warsaw. I went there because I could have a Pap smear done without having to wait for an appointment. However, the doctor advised me to seek treatment at the Institute of Oncology.

I registered and got an appointment very quickly. The doctor did an ultrasound and told me

that the changes were not large, that I would probably just qualify for surgery. He gave me a referral for a CT scan, an MRI, and blood tests for tumor markers. In those days, when I thought about treatment, I was focused on surgery. I viewed chemotherapy as something terrible, very stereotypically. So when I first heard that I was to have chemotherapy, I was completely taken aback. I must have looked very frightened, because the doctor quickly explained that we were aiming for a complete cure, so it was probably worth undergoing chemotherapy. He said it simply, he sounded rational, and it really appealed to me. He brought me down to earth that way. I thought: yes, indeed, it's worth it. I immediately agreed to the treatment. I bought a blonde wig, for a change, because I naturally have dark hair. I didn't want to pretend that the artificial hair was mine. Now, in hindsight, I see that the color of the wig was also very symbolic — I didn't want to pretend that the disease wasn't there, I didn't want to be ashamed of it.

Did you have to stay in the hospital during the treatment?

I came to the hospital for one day for each infusion. I had six chemotherapy sessions. Later, four infusions were combined with daily radiotherapy and a rinse after chemotherapy, because this next therapy was very toxic to the kidneys. At first, I had a fighting attitude, I decided that I would be such a brave Joanna that I would cope with this treatment really well. I was motivated and felt mentally strong. My twin sister, Monika, went to the hospital with me. To make my infusion days more pleasant, she always gave me a gift after chemotherapy.

Which gift do you remember best?

They were all special, they were lovely gestures. But I threw almost all of them away after the treatment was over. I couldn't stand anything that reminded me of that time.

The side effects of chemotherapy can be devastating.

For the first six weeks, I felt terrible for a day or two after the infusion, and then I was just slightly weak for the next few days. After six weeks, it changed. The seventh infusion was combined with radiotherapy, and I went into crisis. I stopped eating, I couldn't eat. My weight started to drop. I am petite and short, and even before treatment I weighed 42 kg.

Even before chemotherapy, my sister started coming to visit me to cook for me. She did everything she could to fatten me up. We knew I had to have something to lose weight

from. I gained weight up to 44 kg. During chemoradiotherapy, I knew that losing weight was dangerous for me. It is for all patients, but I still didn't have much to lose. The radiologist told me at the very beginning that I had to weigh myself every day, that I had to control my weight very carefully. I began to fear that something would happen to me because of my low weight. When I felt very bad, I asked the radiologist if he could keep me in the hospital.

The radiologist said that I looked great and that I wouldn't want to be in that ward. His words calmed me down and eased my anxiety. Physically, however, I felt terrible, and I had to go to the hospital every day for radiation therapy, plus I had chemotherapy once a week. In addition, once a week I had a cleansing infusion after chemotherapy. I did all this automatically - either I was in the hospital or I was sleeping at home. The radiation itself lasts 15 minutes, but you have to get to the hospital and drink half a liter of water before the procedure and walk around the hallway to fill your bladder. I was tired of all this, but also stressed and nervous. Once, when I felt extremely ill, the thought occurred to me that maybe it would be better to stop the treatment. At that point, I was at a stage where I didn't believe that the therapy would help.

Have you lost your fighting spirit?

Yes, but thanks to my loved ones, I persevered until the end of the treatment. In addition to radiotherapy, I also had brachytherapy, which is local radiation.

And then I started thinking magically – I decided that as soon as all the treatments were over, everything in my life would immediately return to normal. I believed that this would be the case – after all, the worst would be over and things would start to get better.

I finished treatment on Friday and returned to work on Monday. I work remotely, so it was possible. I thought that work would help me, that everything would be “normal.” In the mirror, I could see that it wasn't, I still had no hair. I was still nervous, withdrawn, scared.

I realized that I couldn't imagine my future at all. It was as if there was no such thing as a future for me. As part of my treatment at the hospital, I had conversations with a psychologist. However, I didn't feel that this was enough for me. I needed a psychiatrist.

I was given antidepressants and anti-anxiety medication. After about three weeks, I started to see the world a little differently. This coincided with my hair growing back, and I started

seeing my friends again. Before, even though they wanted to be in touch with me, I avoided them. I didn't have the strength for it, but I also didn't want them to see me at my weakest. I was simply ashamed.

You were a hospital patient for months. Everything was subordinated to treatment. Do you still think of yourself as “a patient”?

I haven't closed that chapter because I have my health concerns, but I've put them aside. For the first two months after the end of treatment, being a patient was still the basis of my identity. I don't feel that way anymore, although I still go regularly to the Institute of Oncology for psychotherapy. Follow-up tests showed that I no longer have cancerous lesions.

Did the treatment leave any lasting effects on your body?

I'm getting back into shape. I feel really good now, although I may have suppressed certain things. For example, I used to wake up with body aches. I received a lot of support and love from my loved ones. From my sister and my dad, who returned to Poland from abroad to be with me for six months. But many other people also showed me support.

The treatment has resulted in infertility. No one warned me about this. I officially found out about it after my first chemotherapy session. Unofficially, I heard about it earlier, when I had a private conversation with a gynecologist. He also told me about protecting my fertility — during a private phone conversation. I will use the words of Aga Szućik, a health educator who also had cervical cancer: I didn't know if I wanted to have children, but I wanted to be able to have them. However, after radiotherapy, my ovaries no longer work. Another trace of the disease is my current attitude to life — I enjoy every day, love, and little things more than I used to.

At any stage of your treatment, did anyone talk to you about HPV, which caused your cancer?

No, there was no such conversation at any stage of my treatment.

People who have been diagnosed with cervical changes caused by HPV are advised to get vaccinated against the virus as soon as possible. This helps protect the body from further infections. Your body was seriously affected by the virus, and you did not receive any information about vaccination.



One of the doctors said he wasn't sure if I should get vaccinated at all because it's expensive. Another doctor told me it was too late for vaccination. It was quite a pessimistic message. Maybe I misunderstood the doctors, but I think they could have explained to me exactly when in the future I would be able to get vaccinated. It's in my nature to dig deeper and find out for myself. And the statement that the vaccine is expensive, so it's not worth it for me, makes me feel rebellious. After all, my health is important and anything that helps me is worth it.

The sad thing is that someone else will abandon the idea of vaccination forever after hearing such words. And this may mean a risk of another infection for that person. You can get cancer from HPV. Having undergone treatment for cervical cancer does not protect you from such a scenario.

There is another issue that I explored on my own. I read that after radiation therapy, it is recommended to resume sexual intercourse quickly or to use dilators to prevent the vagina from closing up. However, some of the patients I spoke to were not aware of this.

The lack of information is harmful to them. I understand that doctors have little time for us, but information that is crucial to our quality of life cannot be overlooked. I took care of it myself and went to a private urogynecological physiotherapist. Coming back to vaccinations, it would have been best if I had been vaccinated before treatment, when my body was not yet weakened by chemotherapy. However, no one told me about this. Of course, it would have been best if I had been vaccinated as a child, then I would not have gotten sick. When I was a teenager, there was no state HPV vaccination program. I could also have been vaccinated as a twenty-year-old, but no doctor ever encouraged me to get this vaccination. I tell my friends to get vaccinated and to vaccinate their children. I tell them that vaccinations are free for children.

At first, I didn't admit that I mentioned it because of my diagnosis I would bring it up in messages I exchanged with friends, under the pretext of work — as a health journalist, I could deal with such topics. Many people didn't take up the topic, they just gave my post a thumbs-up emoticon and that was it. I was afraid that such people would soon forget about HPV vaccinations. So I brought up the topic again after some time. One friend took it to heart and vaccinated his daughters. I consider this my personal success.

THE POWER WITHIN ME,,

I would also like to draw people's attention to the fact that HPV infection can happen to anyone, at any stage of life. That is why each of us should be protected by vaccination. I think it is easier for us to talk about these vaccinations in the context of children. Adults find it easier to assume that it does not concern them. Some people are embarrassed to talk about it because the virus is transmitted during intimate contact. Neither youth nor maturity protects against infection, because we have sex at all ages.

Most people will encounter the HPV virus during their lifetime. Our body can fight it off on its own, but without vaccination we cannot be sure of that.

That's why I talk a lot about these vaccinations and I hope that men will also take advantage of them. The HPV virus is associated with cervical cancer in the public consciousness, but that is only one possibility. There are more and more diseases among men who have, for example, anal cancer.

Maybe my story will encourage someone to get vaccinated and protect them from the experience I went through.

COMMENTS

AGNIESZKA
I GRZEGORZ ŚWIĘCH
OFF School Foundation

Everything starts with education. Social awareness, health awareness, and prevention are the hallmarks of developed societies. Education and prevention in the case of HPV are factors that effectively eliminate cancers caused by this virus.

School is a place where we can not only learn, but also effectively take care of prevention in this area. The free vaccination program available to schoolchildren is a factor that makes ours one of the best prevention systems in the world. Let's take advantage of it, because our health and lives depend on it.

IDA KARPIŃSKA
Flower of Femininity
Foundation

I believe that everything starts with knowledge and conversation. The more we talk about caring for ourselves and our loved ones, the greater our chance of avoiding diseases that can be effectively prevented. It is thanks to science and appropriate actions that we have a real impact on our health, lives, and future.

Today, educational institutions are places where young people not only gain information, but can also take advantage of specific solutions to protect themselves from serious diseases. We have access to protective programs, which are a great privilege and support for us. That is why I am appealing to you, women and girls – let's take advantage of this opportunity. Let's take care of ourselves and our daughters, let's make informed decisions that can protect us from suffering and give us a more peaceful future.

ANNA HENCKA-ZYSER
Spa for Cancer. Friends
for Cancer Foundation

It is not only a document addressing important and often painful experiences, but above all a powerful voice in social education. "Education is the passport to the future, for tomorrow belongs to those who prepare for it today" — these words of Malcolm X resonate strongly in every written story.

This album opens our eyes, moves us, and shows us the way. It is a beautiful example of how, through art and testimony, can shape health awareness and point to a realistic path toward prevention and elimination of HPV.

NATALIA SMUŚ
I JAGODA TOWALSKA
Nie Daj Się HPV Foundation

The stories of people affected by HPV-related diseases are moving, but above all, they serve an educational purpose. Such testimonials play a key role in raising public awareness of the risks posed by HPV. By increasing knowledge about the dangers associated with the virus and easily accessible prevention methods (including vaccination), we can realistically reduce the number of people who fall victim to it.

We know from experience that only a small percentage of young people know what HPV is. Young people are eager to listen to their peers or people who are not much older than themselves. That is why we should direct our message to young people through workshops or social media campaigns, because a future free from HPV-related diseases depends on the awareness of young people and their choices.

DOMINIK KUC
Grow Space Foundation

In my opinion, the publication is a great example of how important public health is and how much we need to do to ensure full prevention. The stories touched my heart, and the whole thing makes you think about the need for further education in the area of HPV. There is definitely not enough discussion in the public debate on the safety of children and young people about health education and health safety, including prevention and vaccination against HPV, which is most effective when administered at a young age.

At the same time, the publication breaks a kind of taboo that often prevents honest and scientifically based conversations with young people. It is an example of a comprehensive, reliable source of knowledge and experience for children and young people, which is worth using instead of websites with unverified information or social media. I believe that the publication should be required reading during health education classes for every young person.

ANNA KUPIECKA
OnkoCafe Foundation
— Better Together

HPV is not only cervical cancer — this virus can also cause other cancers. That is why it is so important that we talk about prevention broadly, comprehensively, and without taboos. The album shows human stories in an exceptionally moving way, while at the same time educating and reminding us that vaccinations and tests can really protect health and life. Such initiatives have enormous power — they raise awareness and give people the knowledge they need to make responsible life decisions.



The **HPV ELIMINATION FORUM** is an interdisciplinary initiative established by patient organizations and experts dealing with infectious diseases, oncology, and health education, whose goal is to conduct educational and advocacy activities in the area of human papillomavirus [HPV]. The project aims to continuously monitor data and analyze the situation related to the implementation of the vaccination program, as well as to monitor indicators of HPV-related cancers and other diseases caused by the human papillomavirus in the long term.

The initiators of the **FORUM FOR THE ELIMINATION OF HPV** are non-governmental organizations representing patients and working for public health: the Institute for Patient Rights and Health Education, the OFF School Foundation, the Don't Give in to HPV Foundation, the GrowSPACE Foundation, the SEXED.PL Foundation, the National Organization Flower of Femininity, the OnkoCafe Foundation, and the Spa for Cancer Friends for Cancer Foundation.



Instytut Praw Pacjenta
i Edukacji Zdrowotnej



GROW
SPACE



OnkoCafe
Razem żyjemy





