Interview: Šarūnas Narbutas – President, Lithuanian Cancer Patients' Coalition (POLA)



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09.01.2018

Tags: Lithuania, POLA, Patient Association, Association, e-Health, Regulatory Reform

Šarūnas Narbutas, president at the Lithuanian Cancer Patients' Coalition (POLA), explains the role of patients in shaping the Lithuanian healthcare system as well as the importance of having an integral approach when discussing with healthcare stakeholders to drive progress in the country.

You hold a number of roles in different organizations besides the Lithuanian Cancer Patients' Coalition (POLA). How do you manage to succeed in all of them at the same time?

Nearly all my roles are somehow linked. Currently, I hold five management positions in which I represent POLA and three out of those five are located in Lithuania: chairman of the government fund of promotional public health, board member of e-Health National Board, and member of the National Health Council.

In my opinion, the keys to succeed in different fronts are efficient time-management and an active role in all the positions – not just taking a seat. However, I have to say that POLA and Youth Cancer Europe (YCE), which has a European scope, are the ones that take up most of my attention.

What is the role of patients' organizations in shaping the Lithuanian healthcare system?

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I am proud to confirm that patients' organizations are increasing their influence in the country and, presently, Lithuania has one of the best legal frameworks in the EU in terms of patients' mandatory inclusion in decision-making processes. Indeed, by law, Lithuanian patients' organizations are included on the board of the National Health Insurance Fund (NHIF), the Reimbursement of Medicinal Products and Medical Devices, and on Ethical Committees, among others. Furthermore, we have recently agreed with the Minister of Health that patients' organizations should be included in every new established working group in the Ministry – It is a great accomplishment since it positions patients' presence as a systemic praxis in the national healthcare system.

I would like to stress that POLA is the biggest patients' organizations in the country but, looking ahead, our ambition is to create an umbrella organization that will include other patients' areas. This ambition is still under development but it is the way to go in order to have one clear and solid voice for all patients Lithuania. In this sense, in February 2017 we established the "Lithuanian Patients' Forum" through which we organize active roundtables with the Ministry of Health, other stakeholders such as the NHIF, as well as with industry, and the main patients' organizations in the country. Several promising initiatives are currently being developed as a result of such round tables in which we try to strike the middle ground that ensures the best service for the patient as well as the sustainability of any stakeholder involved.

What do you believe should be improved in this collaboration?

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The biggest challenge that I have encountered when encouraging dialogue with other stakeholders is the lack of an integral approach. The common objective around these discussions should be to improve the national healthcare system for the sake of the patients but, unfortunately, we usually face many individualistic arguments. Nonetheless, the progress made in terms of collaboration deserves recognition and, as any structural change, I believe that with time we will finally develop a more collective approach in such roundtables.

POLA strives towards a sustainable and patient-oriented healthcare system in Lithuania, with a stronger focus on oncology treatment. What are the main areas for improvement in Lithuania in which you are currently focused?

One of our main commitments is to eradicate corruption in the healthcare system since bribes to doctors are still a big issue in Lithuania; indeed, this is also a key priority for the current government.

Secondly, we are really focused on improving communication between patients and doctors since doctors have very limited time to discuss treatment options with patients. As a consequence, we have perceived that cancer patients in Lithuania are not properly following the treatment and I believe that through a more structured communication we could improve patients' adherence to the treatment and consequently reduce the cost of treatment.

Thirdly, it is a fact that palliative care is highly underdeveloped in Lithuania and palliative solutions are important for cancer patients. Indeed, the WHO is criticizing this fact in the country since it stands that any healthcare system should have four elements – prevention, screening and early diagnosis, treatment and rehabilitation, and eventually palliative care – and, as aforesaid, the country is lacking of the latter.

Fourthly, Lithuanians suffering any kind of trauma such as car accident are already receiving psychology consultation services but it is not the case for cancer patients. As POLA, we advocate that oncology patients should also have access to this type of services since they are also facing crisis in their lives.

How would you assess the treatment of oncology patients in Lithuania and their access to the latest innovative treatments?

In 2012 the European Commission reported that Lithuania was the second worst country after Bulgaria in terms of access to innovative treatments amongst all the European countries. Fortunately, this situation has drastically improved and now Lithuania ranks amongst Slovenia and Czech Republic, which are one of the best-ranked countries in Eastern Europe.

Nevertheless, despite the commented progress, the sick fund is still highly limited and its management certainly needs to be further optimized since there are some existing duplicities as well as misuses within it. On top of that, the government is leveraging on the innovative private industry to reduce the patients' access gap through the so-called "claw-back" system, which represents around EUR 12 million out of the EUR 300 million spent by the NHIF on pharmaceuticals. In my opinion, the NHIF should leverage more on private industry's capabilities, not only with discounts but also through other measures such as diagnostic financing and educational trainings.

Considering that you have been closely involved in implementing the Lithuanian e-Health strategy, what have been the results obtained so far and what are the ambitions?

All the healthcare stakeholders, even the government, agree that Lithuania should move the reimbursement criteria from purely cost of the drug to value-based healthcare and e-Health plays a key role in this transition. Unfortunately, we are really far from getting there in Lithuania and this is one of the main concerns of the current reimbursement system.

Hence, despite e-Health being a government priority, it has a very bad reputation within the public domain because of the weak results obtained so far since it started its implementation a decade ago, the continuous change of the approach, and the high amount of money invested (more than EUR 40 million). It is important to consider that there are many challenges affecting its implementation such as the very fragmented data in many different hospitals, the variety of systems used in the healthcare points in the country, and the lack of user friendly interface of the current e-health system. As a consequence, besides the commitment from the government in implementing e-Health, the hospitals are reluctant to use e-health solutions.

In my opinion, it is a shame that a country like Lithuania is lacking e-Health capabilities and its development is a compulsory homework. The government is fully aligned with this ambition and, through the e-Health National Board, we are focused on enhancing all the architecture behind the system to make it more optimal and convenient with new developments based on the latest technology trends. Furthermore, it is really important to see what our European neighbours have done in order to learn from their best practices and, for instance, we recently invited the chief e-Health architect of Estonia due to its similarities with Lithuania as well as their successful implementation of e-Health and we are in touch with WHO experts on e-health development.

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