

Inaugural NCCN Global Academy Gathers Experts from around the World to Discuss Global Cancer Care

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The National Comprehensive Cancer Network® ([NCCN®](#)) hosted its inaugural [NCCN Global Academy for Excellence & Leadership in Oncology™](#): School of Pharmaceutical & Biotech Business on Friday, October 6, 2017, in San Francisco, CA.

Moderated by Robert W. Carlson, MD, NCCN Chief Executive Officer, the program featured two expert panels, the first of which was titled, *Regional Adaptations - Meet NCCN Guidelines® Panel and Collaborative International Experts*. The panelists included:

- David S. Ettinger, MD, Professor of Oncology, [The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins](#); Chair, NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Panels for Non-Small Cell Lung Cancer, Malignant Pleural Mesothelioma, and Thymomas and Thymic Carcinomas; Member, NCCN Guidelines® Panels for Antiemesis and Lung Cancer Screening; Chair, NCCN Guidelines Steering Committee
- Pere Gascón, MD, Professor and Chair of Oncology and Multidisciplinary Knowledge, University of Barcelona; Senior Consultant, Department of Medical Oncology, Clinic University Hospital; NCCN Guideline for Breast Cancer Collaborative International Expert; *La Fundación para la Excelencia y la Calidad en la Oncología (ECO Foundation)*, Barcelona, España
- James L. Mohler, MD, Associate Director and Senior Vice President for Translational Research, [Roswell Park Cancer Institute](#); Chair, NCCN Guidelines Panel for Prostate Cancer; Member, NCCN Guidelines Panel for Prostate Cancer Early Detection
- Fábio Schütz, MD, Medical Oncology Coordinator, *BP - A Beneficência Portuguesa de São Paulo, Brazil*; Department of Medical Oncology and GU Oncology; NCCN Guidelines for Prostate Cancer Collaborative International Expert

Dr. Carlson began the discussion by asking the panelists why they felt it is important to adapt NCCN Guidelines for use in their regions rather than using local clinical practice guidelines. Dr. Schütz mentioned that currently, there are no local guidelines available to oncologists in Latin America. Therefore, they must rely on NCCN resources, noting that the NCCN Guidelines are the high-quality option.

While there are a number of international guidelines options in Spain, said Dr. Gascón, the process of adapting the NCCN Guidelines is helpful to physicians for understanding and ease of use in their native language and circumstances.

Dr. Ettinger stated that the NCCN Guidelines' comprehensiveness across the continuum of care plays a key factor in establishing their importance as a resource. He spoke of his experience developing the NCCN Asia Consensus Statements, and noted how important it is to accommodate for local treatment practices and physiology for ensuring optimal care.

Dr. Mohler spoke about the lengthy adaptation process, the vigor with which the Guidelines are reviewed and the outside perspective provided by local physicians. He also discussed the staggering disparity in conditions of oncology treatment in Africa that he observed derived from an in-person tour of the Uganda Cancer Institute in Kampala, Uganda and the difference this made on his perceptions of the [NCCN African Initiative](#)—an ongoing collaboration between NCCN, the Africa Cancer Coalition, the American Cancer Society, and the Clinton Health Access Initiative to develop NCCN Harmonized Guidelines™ for Sub-Saharan Africa. Dr. Carlson followed Dr. Mohler's insights by commenting on the education NCCN gains through these collaborative adaptations and the important relationships that are then created with local physicians.

According to Dr. Mohler, the adaptation process provides a platform for two-way communication that is unbelievably eye opening, and that physicians in the United States can learn from health care solutions around the world.

The panel also discussed implementation of adapted NCCN Guidelines within their respective regions. In his experience, Dr. Schütz said the uptake of the adaptations for Latin America has been most prevalent in Brazil, adding that the Latin American Cooperative Oncology Group (LACOG)—who collaborated with NCCN on the adaptations—also includes physicians from many other countries within Latin America. He also spoke of the difficulties presented by the disparity of access for those patients having public insurance as opposed to those who have private insurance, and how these difficulties are compounded by government policy and the regulatory environment in public facilities. As a potential solution, Dr. Schütz proposed adapting the NCCN Framework™ so that treatment can be delivered effectively based on the corresponding available resources. He predicted that the NCCN Framework™ would play an increasingly important role in the future to account for resource disparity.

When asked about his own experience adapting the NCCN Guidelines and implementation, Dr. Gascón noted many of the changes for Spain were made based on regulatory and access considerations. He stated that once the European Medicine Agency (EMA) approves a drug, it kicks off a process of price negotiation that makes drug prices vary wildly by country and even by hospital. These differences mean that the adaptations made to the NCCN Guidelines are in the little details, rather than sweeping changes to care. Prior to the adaptation process, NCCN Guidelines were already being widely used in Spain, stated Dr. Gascón. He noted the rapid uptake of the published adaptations in Spain reflect this already existing Guidelines usage. The challenge now, Dr. Gascón said, is to ensure the adaptations are updated to keep pace with the constantly changing state of cancer care.

Dr. Schütz and Dr. Gascón had differences of opinion on the importance of translating the adaptations of the NCCN Guidelines into a region's native language. Dr. Schütz believed it is not always needed as the Latin American doctors are regularly educated in English and feel confident with the language. Dr. Gascón, on the other hand, felt it was a generational question – while the younger generation of physicians are more likely to grow up learning English, the older physicians learned English later in life and therefore are not a comfortable with it. Because of this, he concludes, translation allows for faster reading and comprehension of the adaptation.

In discussing funding for translations and adaptations, Dr. Carlson explained that funds come from a variety of sources, including industry, through General Mission Support (directed or otherwise), support of translations, and licensing and dissemination of the adaptations. He also said that other sources of project funding include support from local governments and other not-for-profit organizations that collaborate with NCCN (i.e. American Cancer Society and Clinton Health Access Initiative for the work in Africa).

Following the discussion, the audience had the opportunity to ask questions of the panel members.

One attendee asked whether health authorities were measuring outcomes in relation to the adaptations of the NCCN Guidelines now available for the regions.

In Spain, outcomes have not yet been monitored, but ECO Foundation would like to do so soon, according to Dr. Gascón. He imagines that outcomes could be measured based on uptake of adaptations and observations of Guidelines concordance.

Dr. Schütz felt that LACOG as an organization is not at a place where they can begin monitoring outcomes due to a lack of data collected in the region. Ideally, he believes that Brazil as a country is evolving to meet these data needs, but that they are not ready yet. Dr. Carlson explained that it is an ongoing discussion.

There was also a question parsing the differences between the health care systems in Mexico and Central America, and whether a South American adaptation could be applied in those regions. Dr. Schütz believed the systems to be similar enough to utilize these adaptations, with only some differences in availability of particular drugs.

In closing, each panel member speculated what the adaptation process would look like in 5 years. Dr. Gascón spoke about widespread use of a robust library of Spanish adaptations of the NCCN Guidelines and Dr. Schütz reiterated that adapting the NCCN Framework™ will play an increasingly important role in the future to account for resource disparity. Dr. Ettinger felt that the NCCN Regional Adaptation Guidelines would be integrated into health information technology and that this would play an important role in collecting outcomes data. He also mentioned NCCN's efforts involving the Categories of Preference to further aid oncology professionals in identifying the most appropriate treatment in a given situation. Dr. Mohler noted that cancer is becoming a more common cause of death due to worldwide longevity. He

agreed with Dr. Ettinger that embedding such knowledge of cancer care in technology would aid in the dissemination of knowledge to local physicians.

The second module was titled, *Global Patient Advocacy and Policy*, and featured the following, multi-stakeholder panelists:

- Marcia Horn, President and CEO, *ICAN, International Cancer Advocacy Network*
- Mihaela Militaru, Senior Director, EU Patient Advocacy & Strategic Partnerships, Oncology, *Merck KGaA, Darmstadt, Germany*
- Cathy Trzaskawka, Head, Global Advocacy, Global Policy, Advocacy & Government Affairs, *Bristol-Myers Squibb*
- Piotr Wysocki, MD, PhD, Professor of Medicine – Clinical Oncology, Head of Chair and Department of Oncology, *Jagiellonian University – Medical College Hospital*; President, Polish Society of Clinical Oncology

To start the second module, Dr. Carlson explained that the panel was asked to focus on opportunities and best practices for collaboration across global advocacy and patient advocacy. The panelists introduced themselves, their backgrounds, and their current efforts in patient advocacy.

Following Dr. Wysocki's introduction and description of the Polish Society of Clinical Oncology's efforts to support and increase the patient advocacy culture in Poland, Dr. Carlson mentioned his own speaking role at one such supportive event in Poland. He asked Dr. Wysocki to elaborate on the relationship that had been built between the oncology physician group and patient advocates, particularly its origins. Dr. Wysocki spoke of the lack of access to drugs due to lag times in regulatory approval. Efforts to appeal to the regulatory bodies proved difficult until they began working with patient advocate groups – this lent strength and persuasion to their demands of the regulatory bodies. Dr. Wysocki concluded by saying that it is the role of the physicians to educate patients, communicate with them and discuss treatment plans, and to set goals and priorities.

Ms. Horn spoke about the variety of patient advocacy efforts across the globe, many of which have grassroots origins. She went on to say that her organization, ICAN, International Cancer Advocacy Network, coordinates these efforts in order to connect people and movements, particularly between advocates and clinicians. Ms. Horn believes that this is a very powerful connection in order to enact change in clinical trials.

The differences in patient advocacy across Europe is very profound, according to Ms. Militaru, whose origin in Romania, and subsequent experience with advocacy groups throughout Europe, have given her an in-depth knowledge of such disparities. In response to a perceived difficulty of advocacy efforts to create policy movements for change, she had created a document, called, "A Europe of Inequalities" which analyzed these differences. Ms. Militaru shared that sometimes pressure from outside a European country, whether by the European parliament or other groups, can assist in enacting change when the solutions within the country fail.

Ms. Trzaskawka pointed out the correlation between Ms. Horn's and Ms. Militaru's points, emphasizing the importance of worldwide coordination and interaction between patient advocacy groups in order to learn from each other, as well as identify solutions and opportunities to collaborate across national borders. Bristol-Myers Squibb hosted such an international advocacy meeting, Ms. Trzaskawka mentioned, in order to foster interaction and allow for shared advocacy experiences to tackle challenges.

Dr. Carlson asked about the Polish physicians' perspective regarding the newly built relationship with patient advocates. Dr. Wysocki said that at first the physicians could not understand why PTOK would be involved in patient advocacy. Over time however, they realized that such efforts resulted in educated patients, which Dr. Wsyocki stated led to an easier treatment process.

Agreeing with Dr. Wysocki's emphasis on the use and power patient advocates can lend a movement, Ms. Trzaskawka went a step further in acknowledging that other stakeholders, such as industry and policy makers, tend to underestimate the effectiveness of patient advocates. She believed that the importance lies in getting the advocates in front of such people to change that perception.

Following Ms. Trzaskawka's point, Dr. Carlson asked the panel about the characteristics of an effective advocate. Ms. Militaru believed that access to research data and social media use is very important, as was the strong ability to use both. She also credited having a background in policy, which she believed had assisted her in her advocacy efforts.

Ms. Horn pointed out that it was important for patient advocates to change the perception of advocacy, especially in the eyes of pharma-biotech companies and academic cancer centers. This could be accomplished, she said, through education, persistence, and firm, clear goals.

Noting that advocacy in high- and middle-income countries had been addressed, Dr. Carlson asked about the efforts in low-income countries and what is being done in these regions. How could groups begin patient advocacy efforts with such low resource levels?

Ms. Trzaskawka fielded this question from the industry perspective, stating that key solutions lay in partnership, education on infrastructure needs, and experience from the previous successes of the HIV/AIDs movements in such regions. She also noted that collaboration must be multi-stakeholder in order to tackle such large and complex challenges. When specifically referencing industry's role in such a scenario, Ms. Trzaskawka mentioned that industry could provide valuable resources – not only funds but also manpower, market research, and education. Ms. Militaru supported the value of industry resources, highlighting the depth of support and expertise in industry.

As a patient advocate, Ms. Horn pointed out that trust is necessary in multi-stakeholder collaborations, and stated that many coalitions' fatal flaws tend to lie in leaving industry and

clinicians out of their efforts. However, Dr. Wysocki cautioned that there are hazards in industry supporting patient advocacy. He said that there could be a certain lack of transparency, which leads to a question of motives.

This led to a question from Dr. Ettinger in the audience for Ms. Trzaskawka and Ms. Militaru, as representatives of industry. He asked whether there were often patient advocacy teams within industry and questioned the goals of such teams.

Both Ms. Trzaskawka and Ms. Militaru agreed that a number of pharma-biotech companies had advocacy teams. Ms. Trzaskawka went on to say that it was an important question to ask. She said that industry support of advocates is often scrutinized, and there is an ongoing discussion of what the appropriate forum is for industry to assist in advocacy efforts.

There are difficulties and constraints on interaction between advocates and industry but both Ms. Trzaskawka and Ms. Militaru believe that the atmosphere and legitimacy of motives are getting much better. According to both, this situation has been improved by both an increase of transparency (due to both technology advances and organizational efforts to be transparent) and a rapid increase in hiring those with patient advocacy background to fill the industry advocacy teams. There have also been very clear guidelines and rules of engagement set out regionally which increases confidence in such collaborations, Ms. Trzaskawka and Ms. Militaru agreed.

Dr. Carlson noted that there tends to be an air of competition in patient advocacy and asked the panel about their experiences with this and the effect this has on advocacy effectiveness. Ms. Horn disagreed with him on this point in terms of policy building and research – she went on to say that she felt that coalitions and cross-stakeholder interactions were very effective and that large organizations were careful not to duplicate efforts. She felt very strongly that interaction with industry was very important and that advocates have a real role to play to enact change. Ms. Trzaskawka agreed and said that industry's role was not to lead the meetings, but to bring advocates together to work on other solutions.

Towards the end of the panel discussion, more questions were taken from the audience. They first questioned why industry tends to build their own internal advocacy teams, and commented that it would be more cost effective and appropriate for industry to fund advocacy groups directly. In response, Ms. Trzaskawka said that she understood the reasoning behind the question, but that the purpose of the two-person advocacy team at BMS is to act as coordinator and liaison between resources within the company and the advocacy groups. Ms. Horn stated that the advocacy teams within industry are vital to strengthening patient advocacy efforts, as industry tends to have the resources and effective connections already in place that can greatly boost these efforts, particularly in policy.

Dr. Wysocki pointed out that stakeholders should be wary of the difference between global efforts to make connections between industry and advocacy groups and national efforts, from his experience in Poland. As a physician, he feels that national collaborations between patient

advocacy groups and industry are suspect, particularly in regards to regulatory efforts, and that it is better that like-minded patient advocacy groups band together on a national level to enact change.

To close the discussion, Dr. Carlson asked the panel what NCCN could do to assist patients and patient advocates directly. Ms. Horn suggested that, in addition to the global outreach already in place at NCCN, an important role NCCN can play is in establishing connections between the clinicians, global advocates, and U.S. patient advocacy groups in order to facilitate international collaborations and problem-solving. Ms. Militaru believed that there is an opportunity for awareness building of the NCCN Guidelines in Europe as well as continued engagement with European groups. According to Ms. Trzaskawka, it is key to involve the patient voice early on in projects, and she recommended NCCN do this in all efforts. Ms. Militaru agreed as it would allow for patients to identify with NCCN and its content through their contribution. Dr. Wsyocki concluded by indicating that there is an opportunity to regionally adapt the NCCN Guidelines for Patients, as this could assist in facilitating understanding between clinicians and patients.

About NCCN Global Academy

Be sure to look out for information on the **2018 NCCN Global Academy Program** coming in the fall of 2018, in **Munich, Germany!**

Pharmaceutical and biotechnology professionals are given the rare opportunity to view the global oncology space, its future and its current operational issues from the provider, payer, and patient advocate perspective. Participants improve their working knowledge of key global business, policy, informational, and operational issues in oncology and gather valuable insights material to developing effective strategies for navigating the various constituencies in consideration of worldwide cancer care issues. Through this interactive program, pharmaceutical and biotech professionals learn from key stakeholders what they view to be the most pressing issues in the global oncology environment and how to apply this knowledge to create mutually successful working relationships.

Professionals from marketing, sales, advocacy, medical affairs, clinical research, international programs, policy and government affairs, and other business areas are better able to serve their customers with improved knowledge of real-world oncology issues after completion of this program.

If you have any questions, please contact [Jennifer Tredwell](#).