



## **IPOPI 17<sup>th</sup> PID Forum** **Primary Immunodeficiencies.** Fighting cancer



### **17<sup>th</sup> PID Forum**

**Primary Immunodeficiencies.**  
Fighting cancer



22<sup>th</sup> April 2021  
14:00-15:30 CEST

Event is co-hosted by: MEPs Irena Joveva (RE, Slovenia) and Deirdre Clune (EPP, Ireland)

*Thursday, 22 April 2021, 14:00 – 15:30 CEST*

Co-hosted by MEPs Irena Joveva (RE, Slovenia) and Deirdre Clune (EPP, Ireland)

## Introduction

On 22 April 2021, the International Patient Organisation for Primary Immunodeficiencies (IPOPI) organised its 17<sup>th</sup> PID Forum entitled “**Primary Immunodeficiencies. Fighting cancer**”. The online event was co-hosted by Members of the European Parliament (MEPs) Ms. Irena Joveva (RE, Slovenia) and Ms. Deirdre Clune (EPP, Ireland), and moderated by Mr. Johan Prevot, Executive Director of IPOPI. Participants highlighted the complex relation between primary immunodeficiencies (PIDs) and cancer. In this regard, IPOPI made key recommendations for addressing the needs of cancer high-risk patient populations such as PIDs. These recommendations included:

1. Cancer screening and diagnosis guidelines to pay attention to high-risk patient populations
2. Specific policy during the formation of multidisciplinary teams to ensure continuity of care for patients with multiple conditions
3. Future cancer research programmes goals to consider the relationship between conditions such as PIDs and cancers

With much European momentum in the field of cancer policy, as seen through the recent publication of [Europe’s Beating Cancer Plan](#), the timing could not have been better for an in-depth exchange of views on the complex relationship between PIDs and malignant tumours.

MEPs Irena Joveva (RE, Slovenia) and Deirdre Clune (EPP, Ireland) confirmed their political support to the PID community when it comes to addressing their needs in future cancer policies.

## Opening remarks



**Opening the 17th PID Forum, Ms. Irena Joveva (RE, Slovenia)** welcomed all speakers and participants and expressed her delight to be able to continue to support the PID patient community. Ms. Joveva emphasized that all stakeholders, including the European Commission, have recognized that not only PID patients are severely affected by cancer but also their families and friends. She therefore highlighted the importance of gaining a better understanding of the links between PIDs and cancer to improve cancer

prevention, diagnosis, and treatment among PID patients and to develop adequate political framework to facilitate this. Due to her interactions with the patient community, Ms. Joveva noted that in the field of PIDs, patients with certain conditions have an increased risk of developing cancer. She highlighted that politicians must take this issue into account when implementing Europe’s Beating Cancer Plan and other cancer and research policies and building the [European Health Union](#). For this reason, she expressed her eagerness to hear more on early detection of cancers when it comes to high-risk patient populations and pointed out that it is crucial for politicians to understand where the current gaps are and in which areas the European Parliament Special Committee on Beating Cancer should focus its efforts.

Furthermore, Ms. Joveva stated that studying the complex relation between PIDs and cancer may have the potential to provide insights on the role of the immune system in preventing and/or controlling cancer, and that gaining a better understanding of these links is highly helpful in diagnosing PID and cancer patients more effectively.

Ms. Joveva concluded by making a reference to the European Union's unique position to coordinate research and maximise the potential of studies by pooling scientific expertise, knowledge, and data.



**Ms. Deirdre Clune (EPP, Ireland)** warmly welcomed all distinguished guests and speakers and thanked IPOPI and Ms. Joveva for involving her in the 17<sup>th</sup> PID Forum. She emphasized that it was relevant to raise the profile of the relation between PIDs and cancer within EU institutions. By pointing out that the European Parliament Special Committee on Beating Cancer is currently working on an own initiative report on strengthening Europe in the fight against cancer, Ms. Clune noted that now is the perfect time to investigate the

synergies between PIDs and cancer, particularly for cancer high-risk patient populations. Following, Ms. Clune expressed her dedication to understanding the complex link between PIDs and cancer and to gathering the necessary information and suggestions to build a comprehensive framework that meets the needs of all patients.

Ms. Clune mentioned that she has been active in the field of screening for rare diseases as earlier screening implies improved diagnosis, disease management, and treatment. By referring to the European Union's key funding programme for research and innovation, [Europe Horizon](#), she pointed out that coordinating actions, sharing information, and pulling resources across the European Union when it comes to public healthcare leads to a better chance of understanding how cancer and PIDs are related. This enables a more appropriate management of these conditions. Ms. Clune concluded by expressing her dedication to improving cancer screening programmes and the quality of care provided to PID patients.

## Setting the scene: PIDs and malignancies

**Ms. Martine Pergent**, President of IPOPI, set the context of the 17<sup>th</sup> PID Forum by pointing out that a specific approach for PID patients suffering from malignancies is needed as tumours are the second leading cause of death for patients with PIDs, right after infections. Within her presentation, she highlighted that the increased risk of malignancies affecting both children and adults with PIDs requires full synergies in the management of the two conditions. Furthermore, Ms. Pergent noted that there is a need to put PID patients at the heart of the health care system, as high-risk patient populations, and to facilitate the creation of multidisciplinary care teams consisting of immunologists, oncologists, haematologists, and specialized nurses.



This should guarantee that PID patients affected by cancer have the chance to benefit from the knowledge of different health care disciplines. Additionally, she emphasized the importance of

enhancing research and innovation and promoting the development of patient registries to gain a better understanding of the complex interactions between PIDs and cancer.

She concluded by presenting IPOPI's call to action, which encompasses (1) the development of cancer screening and diagnosis guidelines that pay attention to high-risk patient populations, (2) the creation of specific policies during the formation of multidisciplinary teams to ensure continuity of care for patients with multiple conditions, and (3) the consideration of the relationship between conditions such as PIDs and cancers within the goals of future cancer research programmes. Considering these political recommendations shall improve the chance of protecting high-risk patient populations, ensure that immunologists and oncologists work hand in hand, and provide insights on the role of the immune system in preventing and/or controlling cancer.

### The immune system and cancer – why is PID research important?



**Prof. Isabelle Meyts**, President of the European Society for Immunodeficiencies (ESID), provided key aspects on why PID research is beneficial for patients and society. While recognizing that most cancer lesions become unnoticed, she pointed out that being aware of phenotypic diversities is crucial as different mutations in single genes and different modes of inheritance lead to different pathogenesis. In this regard, Prof. Meyts

referred to the importance of advancing the so-called *next generation sequencing* to provide precision medicine and treatment to PID patients affected by cancer. As the previous speakers, she highlighted the fact that PID patients have an increased cancer susceptibility by presenting various intrinsic and extrinsic factors, such as uncontrolled lymphocyte proliferation, DNA repair defects, and chronic inflammation, that can contribute to the increased cancer incidence in PID patients.

By mentioning that a recently conducted study indicated that reduced immune surveillance may be less prevalent in specific types of PIDs and cancer than previously expected, Prof. Meyts emphasized the importance of advancing research in the field of PIDs and cancer to guarantee that patients receive the best possible care. This should ensure a patient-centred treatment and increase chances that PID patients affected by cancer have access to different and personalized treatment options.

Prof. Meyts further pointed out that investing and research efforts in PID patients with cancer not only improves the outcomes in PIDs patients with cancer but also teaches a lot about how cancer can be treated separately. She therefore acknowledged that PID research is central when it comes to research on cancer.

Prof. Meyts concluded with three key messages, namely (1) the need for a better understanding of the complex relationship between PIDs and malignancies through further research, (2) the need for raising awareness of underlying PIDs in malignancies and of malignancies as a complication of PIDs among the public, and (3) the need for more research on PID in general and on the management of cancer in PID to optimize outcomes.

## Discussion on treatment & care of patients with PIDs and cancer

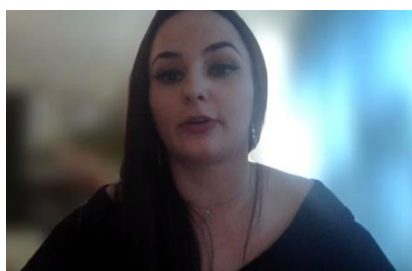
The event continued with an interactive discussion with patient representatives and experts on treatment and care of patients affected by PIDs and cancer. This panel, moderated by **Johan Prevot**, featured **Ms. Antonella Cardone**, Director of the European Cancer Patient Coalition (ECPC), **Ms. Adriana Radovan**, nurse at the Children hospital “Louis Turcanu” in Timisoara, **Dr Fabian Hauck**, from the Ludwig-Maximilians University of Munich, and **Mr. Raf Leijskens**, the parent of a patient with a PID.

The discussion started with **Mr. Johan Prevot** acknowledging that ECPC, the largest European Cancer Patient association, recently published a joint statement on [“making cancer-related complications and comorbidities and EU health priority.”](#) Following, he asked **Antonella Cardone** if she can elaborate more about this statement and how ECPC intends to make comorbidities a part of cancer care policy discussions.

**Ms. Antonella Cardone** highlighted how relevant co-morbidities are for cancer patients. By indicating that almost 90% of cancer patients report at least one co-morbidity condition, she expressed ECPC’s full commitment to raising awareness on cancer co-morbidities. Additionally, Ms. Cardone mentioned that ECPC has successfully worked with various EU institutions to include co-morbidities in Europe’s Beating Cancer Plan. She was pleased to see that cancer is still a priority for policymakers at the EU level but emphasized that its effective implementation is essential to improve the lives of cancer patients. Following, Ms. Cardone acknowledged that cancer related complications and co-morbidities are challenging throughout Europe and called upon EU policymakers to further focus on these issues and develop a renewed focus on cancer by taking a comprehensive and integrated care approach to ensure better treatment outcomes.



Ms. Cardone further elaborated on the creation of an EU cancer platform to monitor the implementation of Europe’s Beating Cancer Plan and referred to the importance of applying a patient-centred care approach within which patients are involved in all aspects of comprehensive care. By demonstrating the need to improve patient data collection methods, Ms. Cardone reflected upon the importance of prioritizing cancer related complications and co-morbidities in research and pointed out that once this is done at the national level, it can also be prioritized at the EU level. She concluded by stating that the EU’s mission on cancer should be the infrastructure to fill the gaps in research on cancer related complications and co-morbidities and advocate for more research on these topics.



Following this, Mr. Prevot turned to **Adriana Radovan** and asked if she has any patients who experience both cancer and PID as well as her perspective on the particularity of the relation between cancer and PIDs.

Ms. Radovan shared her experiences with PID patients affected by cancer that have sought care within the Romanian health care system. By referring to an 8-year-old girl, who was affected by PID and cancer and had to travel over 600 kilometres to receive treatment, she reflected upon the need to

provide improved access to health care systems, particularly in Eastern European countries. She pointed out that many PID patients in Romania only have a chance of being treated from cancer when they are affected by a particular type of PID as there are not enough nurses and doctors to cover all patient needs and as most doctors are only specialized in particular types of PIDs as they have not been trained for other types of PIDs. Furthermore, she mentioned that some Romanian hospitals have only two nurses per day shift and one nurse per night shift for 60 patients and indicated that these nurses are constantly under tremendous pressure.

In terms of improving conditions at the workplace, Ms. Radovan suggested the re-structuring of the Romanian health care system to assign more nurses to patients in addition to minimizing the amount of paperwork that nurses and doctors must cover. She also referred to the possibility of carrying out more outpatient treatments for PIDs in direct response to the limited number of healthcare professionals in hospitals. Ms. Radovan added that EU institutions have recognized the relatively huge gap in access to health care between Eastern and Western EU member states. However, she also demonstrated that there are still many actions that must be taken to improve access to care for all patients and guarantee that PID patients receive timely treatment.

In responding to a question from the moderator about the unmet clinical and research needs in diagnosis and treatment for people with PIDs and cancers, **Dr Fabian Hauck** presented five crucial points: (1) improving diagnosis, (2) improving treatment, including hematopoietic stem-cell transplantation, (3) assessing novel targeted therapies, and (5) identifying PID / Digital Network Appliance Reference Design (DNARD) following primary malignancy diagnosis. Dr Hauck stressed the importance of applying a forward-thinking approach to PIDs and cancer by emphasizing that the medical discipline is still too focused on organs and organ systems. As PIDs and cancer, however, are not only related to organs, Dr Hauck suggested that the medical discipline must move to the next level and break up its traditional organ-related structure by further investigating cells and tissues and moving towards holistic care approaches. According to Dr Hauck, this new framework should, start by enhancing teaching on molecular systems and promote working in the medical discipline to have an increased number of doctors focusing on cells and tissues. Moreover, he proposed the creation of comprehensive cancer centres providing training on molecular systems.



Johan Prevot followed up on this suggestion and asked Dr Fabian Hauck about the structural and personal requirements for a comprehensive cancer centre to improve diagnosis and care for people with PID and malignancy.

While recognizing that short-term investments in such centres will be relatively expensive, Dr Hauck responded that such investments would pay off and be very effective in the long run. In addition, he suggested the development of interlinks between comprehensive cancer centres at the regional, national, and European level. This should not only guarantee that PID and cancer patients benefit from improved care and treatment outcomes but also beneficially impact patients suffering from various other molecular diseases.

By moving forward to the PID patients' area, Mr. Prevot asked **Raf Leijskens** if he could explain his journey as parent of a patient with a PID and a cancer and the challenges faced for more than a decade by him and his family.

Mr. Leijskens thanked the organisers for inviting him to the 17<sup>th</sup> PID Forum to share his experiences with caring for his 14-year-old son, who was diagnosed with a PID at the age of two and with cancer at the age of four. Mr. Leijskens mentioned that his son is affected by a progressive disease and cannot



be independent regarding basic functioning as his fine motoric movements are impaired and as he has balance issues resulting from weaker muscles and loss of muscular strength. Despite these circumstances, he pointed out that his son has a very positive attitude as he is not only greatly supported by his family, friends, and doctors, but also during school and various other activities in his daily life. Following, Mr. Leijskens expressed his gratitude for being able to live in Belgium, where his son can receive support

from a multi-disciplinary care team within 45 minutes of travel time, which is often not the case in other (mainly Eastern) European countries, where patients often travel many hours to receive appropriate care.

Additionally, he emphasized the importance of giving patients the perspective that there are always actions they can work on to improve their daily lives. In this regard, Mr. Leijskens referred to various dimensions that play a key role in improving the care provided to patients with PIDs and cancer. He pointed out that facilitating early diagnosis is essential for parents to prepare on the social dimension and for doctors to collect data to be prepared on the medical dimensions. Additionally, he highlighted that sharing data and investing in research is key to improving patient care.

Mr. Leijskens concluded his interaction with the moderator by acknowledging that early diagnosis enables PID patients and their families to plan accordingly, which leads to improved patient care.

## Open floor discussion

Opening the floor for discussion, one attendee asked if patients who are treated for cancer and just discovered that they have a PID should contact a specialist for their PID or stay with their oncologist. Prof. **Isabelle Meyts** explained that it should not be the patient's responsibility to choose the most appropriate doctor and pointed out that it is the care team's duty to provide the best possible care for patients. Following, she called upon oncologists and PID specialists to facilitate open discussions with patients to provide multidisciplinary care involving all stakeholders.

The next question, which was about potential measures to speed up the development of PID/cancer centres and research, was answered by **Dr Fabian Hauck**. He pointed out that speeding up the development of PID/cancer centres and research is complicated as their quality must remain the same. For this reason, Mr. Hauck suggested focusing on improving sustainability rather than on speeding up the development of PID/cancer centres and research.

Another question was tabled on what national PID organisations can do to improve the care for PID patients who have cancer. **Raf Leijskens** answered this question by stating that national PID

organisations should provide the best possible support and information and ensure that PID patients affected by cancer understand that having cancer is not the end of the journey. Following, he emphasized the importance of encouraging PID patients with cancer to listen to motivational speakers to make them understand that they are capable of dealing with the challenges they are facing. Moreover, a plea was conveyed to investigate if more infrastructure, such as coaching and psychological support, could be provided for both patients and parents in order to increase the quality of life.

Furthermore, participants asked MEPs **Irena Joveva** and **Deirdre Clune** about the aspects the European Parliament Special Committee on Beating Cancer is focusing on and how they view patient organisations bringing-in valuable insights. **MEP Clune** responded that the Committee covers various aspects, including prevention, quality of life, rare cancers, and the social dimension, and seeks to bring diverse stakeholders together during its hearings to improve patient care. She also mentioned that the Committee will use the inputs of engaged stakeholders in the production of a comprehensive report that will include Europe's Beating Cancer Plan. **MEP Joveva** added that the fact that the European Parliament Special Committee on Beating Cancer as such was established, says a lot about the priorities of this mandate in the European Parliament and that the Committee is committed to listen to experts and patients bring their concerns forward.

A question was tabled to Prof. Meyts if it could be assumed that treatment with immunoglobulin can prevent cancer in PID patients even with limited information available on PID and cancer. **Prof. Meyts** replied that although there is limited to no information, it can indeed be assumed that optimal treatment in general, not only immunoglobulin treatment, is a tool to prevent cancer, provided the cancer is caused by chronic inflammation and not by an intrinsic defect like DNA repair defect. However, she also emphasized that collecting long term data is crucial to learn more about these relations.

The next question referred to the timelines on the report on strengthening Europe in the fight against cancer, which is currently prepared by the European Parliament Special Committee on Beating Cancer. Ms. Irena Joveva answered that the presentation of the draft report will likely take place on 15 July 2021 and that there will be deadlines for amendments in September. Additionally, she stated that the first and second considerations of the amendments will take place in October and November, and that the vote in the Committee is planned for the beginning of December of this year.

## Closing statements

Both Ms. Joveva and Ms. Clune expressed their commitment to continue to politically support the PID community and pointed out that they are looking forward to IPOPI's recommendations on PIDs and cancer.

Ms. Joveva thanked all speakers and participants for the insightful contributions they made at the 17<sup>th</sup> PID Forum. As it was agreed by the speakers that the Covid-19 crisis has widened the gap for diagnosing and treating PIDs and cancer, Ms. Joveva emphasized the importance of strengthening data sharing and coordination at the EU level, reducing inequalities within and between EU member states, and investing in digital technologies. Additionally, she pointed out that the measures included in Europe's Beating Cancer Plan could also be used for other people with chronic diseases and for aspects of the European Health Union and indicated that these measures should go hand in hand with the [EU4Health programme](#).





## IPOPI 17<sup>th</sup> PID Forum Primary Immunodeficiencies. Fighting cancer

**Ms. Deirdre Clune** thanked all speakers and participants, particularly those representing PID and cancer patients, for taking part in the 17<sup>th</sup> PID Forum and for providing highly useful input for upcoming policies. She added that the discussions were very informative and worthwhile and concluded the event by emphasizing that she is dedicated to ensuring improvements and meeting patients' needs in policy.