A NNUAL REPORT 2022



ABOUT DIGESTIVE CANCERS EUROPE



Our History

Established in 2018 with founding members Stefan Gijssels (former CEO), Jolanta Gore-Booth (Board Member) and Prof. Dr. Eric van Cutsem (Medical Director) to encompass all types of digestive cancers. DiCE grew from EuropaColon, which was founded in 2004 by Jolanta Gore-Booth and had a focus on colorectal cancer.



Our Mission

To increase overall survival and save 280.000 lives by 2030 through the adoption of current best practices, thereby significantly improving the quality of life of both patients and their carers.

Our Vision

To contribute to early diagnosis and decreased mortality from digestive cancers and to increase overall survival and quality of life.



MESSAGE FROM THE CHAIR

Like a breath of fresh air, after months of online meetings and events, 2022 brought the chance to interact in person with everyone within the organisation and at events! Following the Annual General Assembly and Board Elections in Barcelona, it was an honour to start my three-year term as Chair of the Board. As a Colorectal Cancer (CRC) survivor myself, my journey and experiences drive my dedication to engage and support DiCE in its mission.

Throughout 2022, it was a privilege to work on several impactful policy events including European Colorectal Cancer Awareness Month (ECCAM) launch, a virtual Liver Cancer meeting in October in collaboration with European Liver Patients Association (ELPA), high-level Pancreatic & Gastric Cancers meeting in the European Parliament in Brussels organised in collaboration with United European Gastroenterology (UEG) and Pancreatic Cancer Europe (PCE) and the 3rd Annual DiCE CRC Screening Summit.

LIEVE WIERINCK, DICE CHAIR Thanks to its strong partnerships, DiCE saw tremendous success in 2022. The organisation was generous in giving and beneficial in receiving funding for projects, welcoming new members, forging new collaborations, and organising events for the collective good of improving the lives of those affected by digestive cancers. The hard work of 2022 and several successful EU project proposal submissions have paved the way for a busy 2023.

PROFESSOR DR. ERIC VAN CUTSEM MEDICAL DIRECTOR & CO-FOUNDER





As an organisation, DiCE flourished in 2022. Our Member Organisations (MOs), patients, and carers continued to be well involved and passionate, sharing their stories and having their voices heard in order to achieve change. Throughout the year, we nurtured long-term collaborators and welcomed new ones with the aim of expanding and improving the services we provide to those affected by digestive cancers.

ZORANA MARAVIC CEO

We are delighted about the relaunch of the DiCE Patient Advisory Committee (PAC) in 2022 as part of DiCE's core mission to empower and amplify the voices of digestive cancer patients. Our PAC comprises six cancer patients from across Europe representing all digestive cancers. As cancer survivors and advocates, we are dedicated to utilising our lived experiences to support patients, influence healthcare policies, and collaborate in research and development. In 2023, we will continue our efforts to place patients at the forefront of everything we do.

DAVE CHUTER PATIENT ADVISORY COMMITTEE - CHAIR



BOARD OF DIRECTORS



LIEVE WIERINCK (BELGIUM)

BOARD CHAIR



JENNI TAMMINEN-SIRKIÄ (FINLAND) TREASURER



DAVE CHUTER (UK) BOARD VICE CHAIR



ALINA COMANESCU (ROMANIA) BOARD MEMBER



PROFESSOR DR. ERIC VAN CUTSEM (BELGIUM)

MEDICAL DIRECTOR & CO-FOUNDER



CYRIL SARRAUSTE DE MENTHIÈRE (FRANCE) BOARD MEMBER

PATIENT ADVISORY COMMITTEE



DAVE CHUTER (UK)

PATIENT ADVISORY COMMITTEE, CHAIR



S<u>TEPHEN</u> ROWLEY (UK) PATIENT ADVISOR



E<u>VA BACKMAN</u> (SWEDEN)

PATIENT ADVISOR



PATRYCJA RZADKOWSKA (POLAND) PATIENT ADVISOR



ANDI CÂRLAN (<u>ROMANIA)</u>

PATIENT ADVISOR



ANGELICA SELANDER (SWEDEN) PATIENT ADVISOR

AWARENESS CAMPAIGNS

ECCAM 2022



The European Colorectal Cancer Awareness Month (ECCAM) is an annual public outreach campaign led by DiCE aimed at raising awareness about colorectal cancer, reducing the risk of getting the disease, and promoting the importance of colorectal cancer screening. The 2022 campaign ran through the month of March and was available in 14 languages. The 2022 campaign encouraged the public to seek answers on colorectal cancer. learning about their risk of colorectal cancer, how to reduce it, and when and how to talk to their doctor about getting screened.

The launch event for ECCAM 2022, which took place on 23 February 2022, brought together policymakers, colorectal cancer screening experts, and patient advocacy organisations to discuss ways to improve awareness and make population-based screening available across Europe, also, in relation to the new European Beating Cancer Plan and revised cancer screening guidelines.



Oesophageal Cancer Awareness Month



This annual awareness campaign is aimed at bringing attention to a cancer on the rise, oesophageal cancer. <u>The 2022 campaign</u> focused on the signs and symptoms of oesophageal cancer, while highlighting ways to improve patient treatment and care. DiCE kicked off the month with a social media campaign, in addition to dedicated website page, patient stories, and online promotional materials.

AWARENESS CAMPAIGNS

Liver Cancer Awareness Month



In 2022, DiCE and ELPA partnered for the <u>Liver Cancer Awareness</u> <u>Campaign</u>, raising awareness about the signs, symptoms, prevention and treatment of liver cancer. The focus was on the difficulties of early diagnosis and treatment due to the complexity of this cancer. The campaign materials included a White Paper, Liver Cancer No Patient Left Behind, supported by an Infographic and a Health Economic Factsheet.

During the month of October, DiCE spread awareness messages across social media platforms. Additionally, DiCE organised a high-level, online European policy event titled "Liver Cancer: No Patient Left Behind, Optimising the European Response".

Gastric Cancer Awareness Month



In November 2022, DiCE ran its annual <u>Gastric Cancer Awareness</u> campaign. The campaign included the launch of <u>the Advanced Gastric</u> <u>Cancer Educational Booklet</u>, a resource aimed at supporting patients and carers through the challenges of gastric cancer.

Additionally, <u>two shorter publications</u>, <u>an infographic for patients and a</u> <u>guide for healthcare professionals</u> were also published. DiCE also cohosted a high-level event at the European Parliament to discuss how to beat pancreatic and gastric cancer.

OUR EVENTS

SEVENTH ANNUAL **MASTERCLASS 2022**



The seventh Annual Masterclass ran in parallel to the ESMO World Congress on Gastrointestinal Cancer, taking place from 29 June to 2 July 2022.

It was an occasion for all members of DiCE to meet in person and discuss the latest science- and policyupdates, along with best practices related to digestive cancers. Moreover, during the Masterclass, the Annual General Assembly also took place, culminating with the election of a new Board. For more info, check HERE.



LIVER CANCER: NO PATIENT LEFT BEHIND, **OPTIMISING THE EUROPEAN RESPONSE**



On 12 October 2022, DiCE and the European Liver Patients' Association (ELPA) hosted an online European policy event focused on liver cancer. The event brought together experts, policymakers, and other stakeholders exploring ways to ensure that no patient in Europe is left behind in terms of treatment and prevention of liver cancer. Patient representatives were also present to highlight some of the unmet needs faced by liver cancer patients.

The recording can be found <u>HERE</u>.



OUR EVENTS

THE NEGLECTED HEAVY BURDEN - PANCREATIC AND GASTRIC CANCERS



The event took place on 15 November 2022 to mark Gastric Cancer Awareness Month and World Pancreatic Cancer Day. Together with MEP Cristian-Silviu Buşoi, DiCE, UEG and PCE hosted an event at the European Parliament to raise awareness about the neglected burden of pancreatic and gastric cancers. The event highlighted the lack of screening and early detection for these cancers, which have the lowest survival rates in Europe. It was also an occasion to shed light on potential European actions to improve the situation. For more info, check <u>HERE</u>.

THIRD DICE COLORECTAL CANCER SCREENING SUMMIT

For the third year, DiCE held an online event to unite key stakeholders involved in the design, implementation, and participation in colorectal cancer (CRC) screening programmes across Europe.

This consolidated initiative represented a moment for sharing experiences, points of view, and knowledge on CRC screening programmes, bringing together 20 experts from 15 countries to discuss the Future Challenges and Opportunities of CRC Screening Programmes in Europe. The recording can be found <u>HERE</u>.





POLICY

Putting Digestive Cancers on the Political Agenda



To achieve our mission and goals, DiCE collaborates with various partners to improve policies impacting digestive cancer patients at the National, European and Global levels.

DiCE is a proud member of the European Patients Forum (EPF), the European Cancer Organisation (ECO), The Workgroup of European Cancer Patient Advocacy Networks (WECAN), All.Can, EU4Health Civil Society Alliance, The EU Health Coalition, The International Liver Cancer Movement (ILCM), and Pancreatic Cancer Europe (PCE).

DiCE had the pleasure of cooperating with the United European Gastroenterology (UEG), the European Society for Medical Oncology (ESMO), the European Organisation for Rare Diseases (EURORDIS), the European Alliance for Personalised Medicine (EAPM), the European Association for Study of the Liver (EASL), The International Liver Cancer Association (ILCA) European Liver Patient's Association (ELPA), European Federation of Pharmaceutical Industries and Associations (EFPIA).

In 2022, after COVID-19 restrictions were lifted, DiCE took advantage of the European Parliament reopening and organised its first meeting in the European Parliament in partnership with UEG and PCE. In conjunction with the event, several DiCE Member Organisations secured meetings with offices of the Members of the European Parliament to present our policy asks.

POLICY



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Pancreatic and gastric cancers have been neglected for way too long and their burden has been growing. We need to ensure our policies are not empty promises and provide more funding for research into prevention and treatment.

MEP CRISTIAN-SILVIU BUŞOI

DiCE has followed the legislative files high on the political agenda and implementation of Europe's Beating Cancer plan to ensure that digestive cancer patients' voices are considered. We welcomed the EU Cancer Screening Recommendations that included CRC and gastric cancer and are pleased that Zorana Maravic is involved in The European Commission Initiative on Colorectal Cancer (ECICC).

We are grateful to Members of the European Parliament, Joint Research Centre, World Health Organisation and European Commission for the support they offered to us throughout the year.

We are looking forward to future endeavours together.

This work will be continued in 2023, with Pharmaceutical Legislation, Recommendations on vaccine-preventable cancers and efforts to capitalise on Europe's Beating Cancer being at the forefront of the DiCE agenda.



Patients should receive continuum support thought their journey with clear and understandable information on the available treatment options and support services.

77







To reduce the burden of CRC, my colleagues and I in the European Parliament will continue working to ensure that the European project delivers on its economic and social promises.

MEP SARA CERDAS



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OUR MEMBER ORGANISATIONS



The DiCE umbrella of organisations has grown to around 40 national Member Organisations (MOs) from the WHO European Region.

We aim to give a voice to the 949,000 people diagnosed with digestive cancers every year in Europe, as well as the 1.6 million survivors and the families of the 606,000 patients who die every year. Working together we increase the collective impact of the patient voice by:

- Forming a larger community: building capacity, sharing best practices, learning skills and fortifying knowledge.
- Building together a stronger voice as a part of a broader picture.
- Increasing patient access to decision-makers at all levels.

UPDATES FROM OUR MOS

In 2022, two rounds of unrestricted grants were distributed to support Full and Associate DiCE Members. A total amount of 28.200 EUR was awarded. Below we presented three examples of the activities that were funded.



Turkey's Dance with Cancer Association raised awareness about gastric cancer through social media and a webinar tackling early diagnosis, treatment methods, and nutrition for gastric cancer. With their campaigns, they reached over 13,000 people.



POLA is a community for cancer patients and their families in Lithuania that offers discounts and programs through a membership card. They are launching a new project to provide emotional and practical support for cancer patients and their caregivers.





Lebanon's SAID NGO organised a March for Colon Cancer walkathon in Beirut, which attracted over 800 participants and included various activities such as a musical show, gym classes, and distribution of awareness materials and free test kits.



UPDATES FROM OUR MOS



For the 2022 edition of the Wolfram Nolte Memorial Award, we received five great projects from Belgium, France, Italy and Portugal. One project, however, exceeded the others with the highest score: it was the project from EuropaColon Portugal on organising a training workshop for patients with ostomy. The prize amounted to 5.000 EUR.



Tzav Meni'a, our Associate Member based in Israel and focused on colorectal cancer, has implemented two new projects in 2022. A mentorship program called "Together along the Road" for patients and caregivers, as well as an educational video about pathologic testing of tumours.





Through a series of online videos, our Dutch Member, Stichting Darmkanker brought the message "Alarm voor de Darm" (Alarm for the colon) to the general public. Using the celebrity patient endorsement of Ruud de Wild, Dutch Radio DJ and TV presenter, the foundation ran a successful campaign towards saving lives.





Two new members joined DiCE in 2022! OnkoAlianse, a Latvian umbrella organisation that helps defend the interests of oncology patients, and Codice Viola, an Italian pancreatic cancer patient organisation working to improve the overall survival and quality of life for people living with this cancer.



PUBLICATIONS

Pancreatic Cancer White Paper



Consulting with pancreatic cancer patients, representatives of cancer patient organisations, and leading pancreatic cancer healthcare professionals, DiCE published "Pancreatic Cancer: The Time To Act Is Now 2022", A White Paper calling for urgent action in 10 key areas.

It highlights the critical unmet needs in pancreatic cancer from the patient's perspective, ultimately improving patient care and outcomes in this very challenging disease.

READ IT HERE!

Nutrition Position Paper



"The Impact Of Nutrition On The Lives Of Patients With Digestive Cancers" is a DiCE Position Paper on the topic of nutrition. It aims to share the patient community's perspective on the status and importance of nutritional intervention in digestive cancers.

This is an advocacy manuscript presenting data on the topic and analysing the current situations and the challenges for nutrition in digestive cancers. It highlights the importance of integrative nutrition in treating digestive cancers and advocates for equitable and universal access to nutritional intervention for all patients.

READ IT HERE!

PUBLICATIONS



All Cancers

• Nutrition in Digestive Cancers - Fact Sheet

Colorectal Cancer

- Infographics Why Getting Personal Can Be Lifesaving?
- 3rd DiCE CRC Summit Report
- Why Getting Personal Can Be Lifesaving?
- Why Getting Personal Can be Lifesaving? A guide for healthcare professionals
- <u>Why Getting Personal Can Be Lifesaving? A Patient Guide on</u>
 <u>Biomarkers in Metastatic Colorectal Cancer</u>

Gastric Cancer

- Advanced Gastric Cancer Educational Booklet
- Gastric Cancer: HER2 Treatment (for HCPs)
- Gastric Cancer: HER2 Testing (for patients) Infographic

C DICE TEAM 2022



ZORANA MARAVIC (SERBIA)

CEO



GHISLAINE GERBIER (FRANCE)

ADMINISTRATIVE MANAGER



ALEKSANDRA KACZMAREK (POLAND)

PUBLIC POLICY MANAGER (FROM MAY 2022)



MARIANNA VITALONI (ITALY)

MEDICAL & SCIENTIFIC PROJECT MANAGER



NATASHA MÜNCH (US)

SENIOR MEDICAL & SCIENTIFIC PROJECT COORDINATOR



RUEL JACOB (PHILIPPINES)

COMMUNICATIONS MANAGER (FROM AUG 2022)



GIULIA BARENGHI (ITALY)

POLICY & PUBLIC FUNDING MANAGER (UNTIL MAY 2022)



CATIE YOUNG (AUSTRALIA)

COMMUNICATIONS MANAGER (UNTIL SEPT 2022)



ANA MONTEIRO (PORTUGAL)

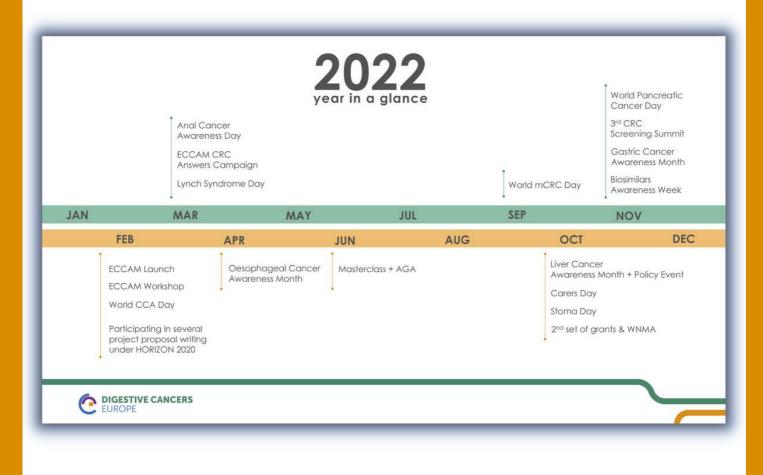
COMMUNITY LIAISON OFFICER (FROM MAY 2022 UNTIL DEC 2022)



TENA LAVRENČIĆ (CROATIA)

SOCIAL MEDIA OFFICER (UNTIL NOV 2022)

THANK YOU!







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> For more information: www.digestivecancers.eu

