

Annual Report

2020-2021

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ABOUT ECL

The Association of European Cancer Leagues (ECL) is a non-profit organisation that unites, supports and represents cancer leagues across the WHO European region. Established in 1980 by prominent NGOs and experts, ECL is based in Brussels (Belgium).

The vision of ECL is for a Europe Free of Cancers and ECL's mission is to influence and improve cancer control and cancer care in Europe. This is done by providing a forum and voice for experienced cancer societies and supporting new entrants facilitating collaboration and knowledge sharing, primarily in the areas of cancer prevention, access to medicines and patient support, as well as creating opportunities to advocate for these issues at the EU level.

Since its establishment, ECL has grown in achievements and leadership, earning a reputation for being an independent and objective voice in cancer control. ECL's eminent status in Europe today is due to the successful collaboration with

its members, other NGOs, research institutes and global and European institutions, including the WHO's International Agency for Research on Cancer (IARC), the European Commission and the European Parliament.

ECL is a full member of the Health and Environment Alliance (HEAL), the European Public Health Alliance (EPHA), the European Cancer Organisation (ECO), the COVID-19 and Cancer Global Taskforce, and the European Commission's eHealth Stakeholder Group.

ECL is also an affiliate member of Cancer Prevention Europe (CPE) and of the COVID-19 and Cancer Global Modelling Consortium.

ECL has a memorandum of understanding with the Smokefree Partnership (SFP) and the Catalan Institute of Oncology (ICO). ECL is also among the eligible not-for-profit organisations regularly consulted by the European Medicines Agency (EMA) and an observer in the Low Voltage Directive Working.



MESSAGE FROM THE PRESIDENT



I have now been in post as President of ECL for over one year. A year in which the SARS-CoV-2 has turned the global spotlight onto healthcare and upended medical services. It has exposed the frailties of existing systems but also highlighted examples of nimble innovation and success.

2020 and 2021 were billed as years of opportunity for European cancer policy with the promise of both an EU Cancer Mission and Europe's Beating Cancer Plan to be finalised and launched. Those of a more pessimistic mind may consider that the destructive force of the SARS-CoV-2 knocked cancer out of the EU's primary focus and that ambitions must therefore be adjusted downwards. However, COVID-19 has created a great awakening for many at the top levels of the EU: that health cooperation between member states is not just a pleasant afterthought to the traditional core EU business on economic matters. It has taken a shattering pandemic, and its terrible consequences, to force a sudden realisation that health cooperation is at the very heart of what the EU should exist for.

We now have grown to 30 member leagues in 25 countries. I would like to thank all our members, especially those leading and actively participating in our working groups. ECL has achieved significant recognition internationally as the representative voice of cancer societies across Europe. We continue to support and grow our 29 strong membership of cancer leagues.

Much of our focus over the last 24 months has been on building and nurturing relationships with partners to raise awareness of the role cancer leagues can play in the wider dialogue around cancer control and in the context of. Our

challenge now is to ensure the

implementation of Europe's Beating Cancer Plan works well for patients, survivors, caregivers, and citizens, and meets the needs identified by the European cancer community.

Despite the ongoing pandemic, amongst other things, we have successfully celebrated our 40th anniversary, launched the 7th Tobacco Control Scale report at the European Conference on Tobacco or Health (ECToH 2020), established a new Prevention & Early Detection Working Group (P&EDWG), contributed to shaping implementation of Europe's Beating Cancer Plan and the Pharmaceutical Strategy for Europe, implemented a series of successful virtual policy dialogues, joined a new EU-funded project on cervical cancer screening and organised European Week Against Cancer (EWAC) 2020 and 2021 fully online.

I would like to extend my warmest thanks to our hard-working members, partners and collaborators for everything we have achieved together, and of course, to our proactive ECL Board Members and Secretariat. Our impact on cancer control and care in Europe and our good reputation are very much based on the strong national influence of the national and regional cancer leagues, and the excellent work our staff and Board Members are doing.

A handwritten signature in blue ink, which appears to read 'Rui Medeiros'.

Professor Rui Medeiros, ECL President





ECL EXECUTIVE BOARD

ECL is governed by a Board of Directors. The Executive Board is responsible for ECL's strategy, directions and main activities, organisational development, communications and relationship with members and other relevant organisations.

Board members are volunteers and do not receive remuneration for their roles. Our Board

of Directors consists of representatives of our members. The Board of Directors is elected via the General Assembly of member leagues.

ECL is grateful for their support, dedication, and active contributions to the work of ECL throughout the years, as well as for their valuable advice in guiding the ECL Secretariat in its activities.

The 2020 Executive Board comprised of the following 6 members:



Rui Medeiros, President,
Portuguese League against Cancer



Elizabeth Hjorth, Vice President Legal
Counsel, Danish Cancer Society
(until November 2021)



Nicolas Philippou, Treasurer,
Cyprus Association of Cancer Patients
and Friends



Darina Sedláková,
League Against Cancer Slovakia



Lucienne Thommes,
Foundation Cancer Luxembourg



Emma Greenwood,
Cancer Research UK
(until November 2021)

The 2020 Executive Board comprised of the following 6 members:



Sakari Karjalainen, President,
Cancer Society of Finland
(until November 2020)



Rui Medeiros, Vice President,
Portuguese League against Cancer



Nicolas Philippou, Treasurer, Cyprus
Association of Cancer Patients and
Friends



Elizabeth Hjorth, Legal Counsel,
Danish Cancer Society



Darina Sedláková,
League Against Cancer Slovakia



Lucienne Thommes,
Foundation Cancer Luxembourg

Following the statutes and by-laws stipulating that the Board should meet at least four times a year, the ECL Executive Board met:

- **5 times in 2021:** on 26 February, 11 May, 13-14 September, 4 November and 20 December.
- **5 times in 2020:** on 24-25 February, 11 June, 8 September, 2 November and 2 December.

In addition to the meetings and teleconferences, there were regular email correspondences and side meetings at online cancer conferences and events between Board members, especially the President, Vice-President and Treasurer, and the Secretariat.

Notable agenda items for Board meetings included the impact of COVID-19 on cancer leagues, the monitoring of activities being implemented through the European Commission's Operating

Grant, opportunities under the new EU4Health programme and Europe's Beating Cancer Plan, ECL's participation in Joint Actions (Innovative Partnership Action Against Cancer (IPAAC) and on Vaccinations (EU-JAV) and in other EU-funded projects (CBIG-SCREEN, WASABY and MyPEBs). The Board also advised on the organisation of the ECL annual Honorary Awards, the 2020 European Conference on Tobacco or Health, and the establishment of a new Prevention and Early Detection Working Group.

During every Board meeting, the ECL secretariat reported on the status of the main areas of work, including tobacco control, prevention, patient support, access to medicines, advocacy and activities of the Youth Ambassadors for the European Code Against Cancer.





ECL SECRETARIAT

ECL is managed by the Executive Director and her team.

ECL's activities and resources have remained constant since the first successful application for EU co-funding in the form of an Operating Grant 2015-2017. The Secretariat's activities are planned and implemented in line with ECL's vision and mission, the ECL Strategy 2019-2021, and the commitments taken under the Operating Grant for the period 2017-2021 and specific activities in 2020 and 2021. ECL is a fully compliant member of the EU Transparency Register (Number 19265592757-25).

ECL Secretariat staff

The core staffing at the ECL Secretariat in Brussels in 2020-2021:

- **Wendy Yared**, Director at 100%
- **David Ritchie**, Cancer Prevention Manager at 100%
- **Ginevra Papi**, Communications & Public Relations Officer at 100%
- **Anna Prokúpková**, Advocacy & Project Manager at 100% (until December 2020)
- **Luk Joossens**, Tobacco Control Advocacy Officer at 20% (until March 2020)
- **Florence Boivin**, Office Manager Contractor, at 10%-30% (from February 2021)
- **Anne Revell**, Office Manager Contractor at 25-50% (until March 2021)
- **Linda Abdelall**, Policy & Project Officer at 100% (from March 2021)
- **Thomas Tharakan**, Operations & Finance Officer Contractor, at 10-30% (from June 2021)

Additionally in 2020-21:

- **Meritxell Mallafré-Larrosa**, Research Associate, freelance
- **Adele Barlassina**, Project Assistant at 100% (until April 2021)
- **Simina Peterfi**, Youth Ambassadors Coordinator at 100% (until August 2021)
- **Flore Rennesson**, Policy & Project Intern at 100% (from October 2021)
- **Anamaria Szabo**, Communications & Community Intern at 100% (from October 2021)

More information about the ECL Secretariat's current staff members is available [here](#).

ECL Strategic Goals 2019-21

Goal 1: Influence cancer control policies

Maintain and strengthen ECL's position in influencing European cancer control policies. Work for and support the development and implementation of national cancer control programmes, this includes European collaboration, establishment and support to cancer registries, epidemiological, clinical and basic cancer research in all European countries.

Goal 2: Promote cancer prevention

Promote the evidence-based knowledge to prevent cancer, such as messages of the European Code Against Cancer in order to reduce cancer incidence and mortality in Europe. Advocate for the implementation of governmental policies and actions supporting messages of the European Code Against Cancer.

Goal 3: Enhance access to cancer screening and early diagnosis

Enhance access to scientifically proven effective and quality-controlled cancer screening programmes in accordance with EU guidelines and relevant international evidence. Support early detection of cancer.

Goal 4: Ensure equal access to high value cancer treatments for all cancer patients in Europe

Advocate for equal access to effective cancer treatments and therapies for all European patients by insisting on accessibility, sustainability of the healthcare system and transparency of medicines prices.

Goal 5: Develop actions supporting cancer patients, survivors and caregivers

Improve support services and ensure access to high quality treatment interventions and care for all cancer patients, survivors and caregivers in Europe. Promote the rights and address inequalities throughout the whole patient pathway.

Goal 6: Grow membership and increase impact of ECL in Europe

Actively contribute to the growth of the organisations by promoting ECL's work in Europe. Boost the impact of ECL by strengthening its voice in cancer control advocacy. Ensure membership of relevant cancer societies in ECL.

ECL's 2019-2021 Strategy can be downloaded [here](#).

ECL Secretariat Activities

Convening

We convene our members, partners, collaborators and interested stakeholders for discussion and exchange, building consensus and co-ordinating activities, including through events and campaigns.

We believe in collaboration, bringing together those who share our mission and vision to promote multidisciplinary for the benefit of patients, as well as advocating for better cancer control policies in

Europe and beyond.

Events

ECL was active in varying capacities, as (co-) organisers, speakers, dissemination partners or active participants in 232 webinars, conferences, meetings, workshops and events in 2021 and 179 in 2020.

ECL responded regularly to requests for information and data for briefings, speeches and presentations from our member leagues, Members of the European Parliament, European Commission civil servants, health-focused civil society organisations and journalists.

Networking

ECL met and exchanged information regularly throughout the year with various cancer and/or health-focused organisations and institutions to strengthen collaboration and avoid duplication of efforts, notably with WHO's International Agency for Research on Cancer (IARC), the European Agency for Safety and Health at Work (EU-OSHA), Smoke Free Partnership (SFP), the European Public Health Association (EPHA), Health and Environment Alliance (HEAL), European Cancer Patient Organisation (ECPC), the European Society for Paediatric Oncology (SIOPE), European Oncology Nursing Society (EONS), the European Patients' Forum (EPF), European Society for Medical Oncology (ESMO), and the European Alcohol Policy Alliance (EUROCARE).

Capacity building

We act as the voice of cancer leagues, amplifying the important work of our members at the national and regional level. On behalf of member leagues, we coordinate various activities, including three working groups approved by the General Assembly.

Led by chairs, vice-chairs and subgroup leaders from our member leagues, the working groups have been established to facilitate consensus and joint projects around 3 key thematic areas: cancer prevention & early detection, access to medicines and patient support.





Patient Support Working Group (PSWG)

Established in 2007, the PSWG is the oldest of our working groups. PSWG members are cancer care experts working for cancer leagues across Europe who seek to share best practices, develop guidelines and other resources to raise awareness of issues affecting patients, survivors and caregivers, as well as advocate to improve quality of care at the national and European level.

In 2020-21, the ECL secretariat co-ordinated and supported the ECL PSWG, chaired by the Dutch Cancer Society (until April 2021) and co-chaired by the Portuguese League Against Cancer.

Access to Medicines Task Force (A2M TF)

Since 2016, the ECL Secretariat connects public affairs, advocacy, and research staff from cancer leagues with the aim of making safe and effective medicines available to all cancer patients in Europe, by insisting on accessibility, availability, affordability and increased transparency related to medicine prices, ultimately leading to sustainability of healthcare systems.

In 2020-21, the ECL secretariat co-ordinated and supported the ECL A2M TF, chaired by Stand up to Cancer Flanders since September 2019.

Prevention & Early Detection Working Group (P&EDWG)

In June 2020, the ECL Secretariat established a new, permanent working group on cancer prevention and early detection as a standing entity, following a consensus statement produced in 2019. The P&EDWG connects health promotion, research and communication specialists from member leagues. In 2021, steps were taken to identify and agree upon areas for the initial subgroups, which shall identify and agree upon specific objectives to guide the practical actions.

The ECL Secretariat convened member leagues to discuss the issue of enabling informed decision-making about cancer screening participation, the issue of restarting cancer screening in the aftermath

of the lockdowns imposed due to Covid-19, and the update of the Council recommendation on cancer screening (2003).

The Secretariat also convened experts, including the International Agency for Research on Cancer (IARC) and CPO Piemonte (WHO Collaborating Centre for Early Detection in Cancer), to continue discussions on the future implementation reports on cancer screening in the EU and the development of the 3rd implementation report of the Council recommendation on cancer screening (2003).

ECL Youth Ambassadors for the European Code Against Cancer (ECL YAs)

Since 2015, the ECL Secretariat supports, trains and empowers the ECL Youth Ambassadors (ECL YAs) for the European Code Against Cancer (ECAC). The ECL YAs programme is a decentralised network of students and young professionals from different backgrounds, countries and ages who share a deep conviction that cancer can be defeated by following the 12 messages of the ECAC.

In 2020-21, the programme counted 68 members from 39 countries across the WHO European region. ECL secretariat co-ordinated and supported ECL YAs to organise a variety of individual and joint activities, projects, campaigns and events.

European Fair Pricing Network (EFPN)

In 2020, ECL supported the online launch of the EFPN co-organised with partner cancer societies and the Netherlands Cancer Institute (NKI). This network aims to push for fairer prices of cancer medicines while upkeeping the innovation pipeline and early access for patients to promising new medicines. In 2020, ECL supported advocacy and communications activities and actively participated in the meetings of the steering committee.

Advocacy

On behalf of our members, we strive to be a leading organisation in influencing cancer policy and advocating at the European level, as well as a useful

resource to European institutions to convene and facilitate across countries and professions.

We advocate on key policy issues, speaking with one voice on behalf of cancer leagues, to enhance the impact of their expertise and experience.

MEPs Against Cancer (MAC) Interest Group

ECL provides the Secretariat for the MEPs Against Cancer (MAC) Interest Group at the European Parliament. In 2020-21, ECL ensured that the group continued to have a strong leadership, reviewed its action plan, had an external stakeholders meeting as well as an internal strategic meeting.

EU initiatives, joint actions & projects

ECL increased interactions with the European Commission (DG SANTE), particularly about Europe's Beating Cancer Plan and the impact of COVID-19 pandemic on cancer care services. ECL held regular teleconferences with CHAFAE and DG SANTE and provided written contributions for briefings and speeches at their request.

ECL continued to be represented in 2020-21 in the European Commission Initiative on Breast Cancer (ECIBC)'s Quality Assurance Scheme Development Group (QASDG) by ECL's Cancer Prevention Manager.

ECL continued its work as an associated partner in the Horizon 2020 project MYPeBS (My Personal Breast Screening) and in the pilot preparatory action WASABY (Water and Soil contamination and Breast Cancer risk in Young Women). In March 2021, ECL joined the CBIG-SCREEN project (Working collaboratively with vulnerable women to identify the best implementation gains by screening cervical cancer more effectively in European countries).

As part of the EU Joint Action Innovative Action on Cancer Control (iPAAC), ECL participated in various teleconferences throughout the year, hosted and co-organised the virtual co-creation meetings of two physical Work Package on Prevention

(WP5) on 'Cancer Prevention & the European Code Against Cancer' with CSF and IARC on 28-29 April 2020.

As part of the EU Joint Action on Vaccinations (EU-JAV), ECL took part in teleconferences with the French Ministry for Solidarity and Health, leading the work package on sustainability (WP8), submitted regular progress updates on planning by the Youth Ambassadors, as well as implemented and evaluated a Youth Competition focusing on HPV vaccination.

In July 2020, ECL joined the relaunched European Commission's eHealth Stakeholder Group. In April 2021, ECL joined the Joint Action Joint Action Towards the European Health Data Space (TEHDAS).

In May 2021, ECL joined the Europe's Beating Cancer Plan Stakeholder Contact Group set up by the European Commission on the EU Health Policy Platform in view of the implementation of the Cancer Plan. In October 2021, ECL applied to join three Thematic Groups within the Stakeholder Contact Group, namely (i) prevention, (ii) early detection, diagnosis and treatment and (iii) quality of life.

Regarding cancer research, the ECL secretariat joined a joint open letter to health ministers, attachés and Brexit negotiators regarding the importance of EU-UK collaboration in cancer research after Brexit, January 2020, and published a reflection paper on the interim report of the Cancer Mission of Horizon Europe in July 2020.

Cancer Screening & early detection

ECL continued its strong advocacy and capacity building focus in cancer screening, by collaborating with a range of leading experts in cancer screening on "Key issues that need to be considered while revising the current annex of the European Council Recommendation (2003) on cancer screening". This paper has formed the basis of ECL's advocacy

Recognising the adoption of the Global Strategy for the Elimination of Cervical Cancer as a Public





Health Problem in November 2020, ECL has collaborated with experts and member leagues to argue for Europe and the European Union to play its role in achieving the 2030 targets of the Strategy. Following a public webinar to commemorate World Cancer Day 2021, ECL coordinated a campaign to devise and promote a joint statement outlining the seven priorities for Europe regarding the elimination of cervical cancer as a public health problem.

Tobacco Control

ECL's Tobacco Control Advocacy Officer led on the drafting and design of the new edition of the 2019 Tobacco Control Scale report in collaboration with the Catalan Institute of Oncology (ICO) - which was officially launched at the 8th European Conference on Tobacco or Health (ECToH) in Berlin in February 2020.

The European Conferences on Tobacco or Health (ECToH) are organised every 3 years under the auspices of the Association of European Cancer Leagues (ECL) and by prominent cancer leagues. These conferences attract hundreds of committed scientists, policy-makers, researchers, health professionals as well as others strongly committed to fighting against tobacco.

In 2020, ECToH took place at the same time and at the same venue as the German Cancer Congress (DKK) - the largest oncological expert conference in the German-speaking area. To learn more about ECToH 2020, please visit the ECToH Round Up report.

The next ECToH edition, in 2023, will be hosted by the Spanish Association Against Cancer (AECC) in Madrid.

HIGHLIGHTS OF 2020-2021

25-31 May 2021

Virtual European Week Against Cancer (EWAC)

In 2021, the EWAC campaign had one of its most successful and productive years yet! The EWAC campaign of 2021 focused on shaping the implementation of Europe's Beating Cancer Plan (#EUCancerPlan) – a core priority of the European Commission in the 2019-2024 legislative term.

During #EWAC2021, ECL aimed to raise awareness about the flagship initiatives and supporting actions outlined in the Communication on Europe's Beating Cancer Plan, as well as promote cancer leagues' recommendations for European and national decision-makers.

Overall the campaign was a great success and really highlighted the resilience, perseverance and inclusivity of the cancer community in Europe.

7 DAYS OF #EWAC2021

#EWAC2021 will take place between Tuesday 25 May and Monday 31 May 2021. Each day will focus on a different aspect of the cancer control continuum.

 PRIMARY PREVENTION Tuesday, 25 May	 EARLY DETECTION Wednesday, 26 May	 RESEARCH Thursday, 27 May
 ACCESS TO TREATMENT Friday, 28 May	 PATIENTS & SURVIVORS Saturday, 29 May	 DIGITAL HEALTH & CARE Sunday, 30 May
 TOBACCO CONTROL <u>World No Tobacco Day</u> Monday, 31 May		

⇒ Check out the [EWAC drive](#) to find useful materials, including logos, visuals for each day and ready-made messages for your social media channels.

HOW CAN YOU HELP?

Everyone has a role to play in the fight against cancer! Please support the campaign - even if you only have 5 minutes to spare.

HAVE 5 MINUTES TO SPARE?

1. Check out [EWAC's official webpage](#).
2. Share/post messages and images on Twitter, Facebook & LinkedIn.

HAVE 30 MINUTES TO SUPPORT #EWAC2021?

1. Check out [EWAC's official webpage](#).
2. Support [#EWAC2021](#) on Twitter, Facebook and LinkedIn by linking, sharing and posting [our material](#) or your own content.
3. Add the [EWAC frame](#) to your Facebook profile & the [EWAC Twibbon](#) to your Twitter profile.
4. Add an [EWAC banner](#) to your email signature.

WHAT ELSE CAN THE CANCER COMMUNITY DO?

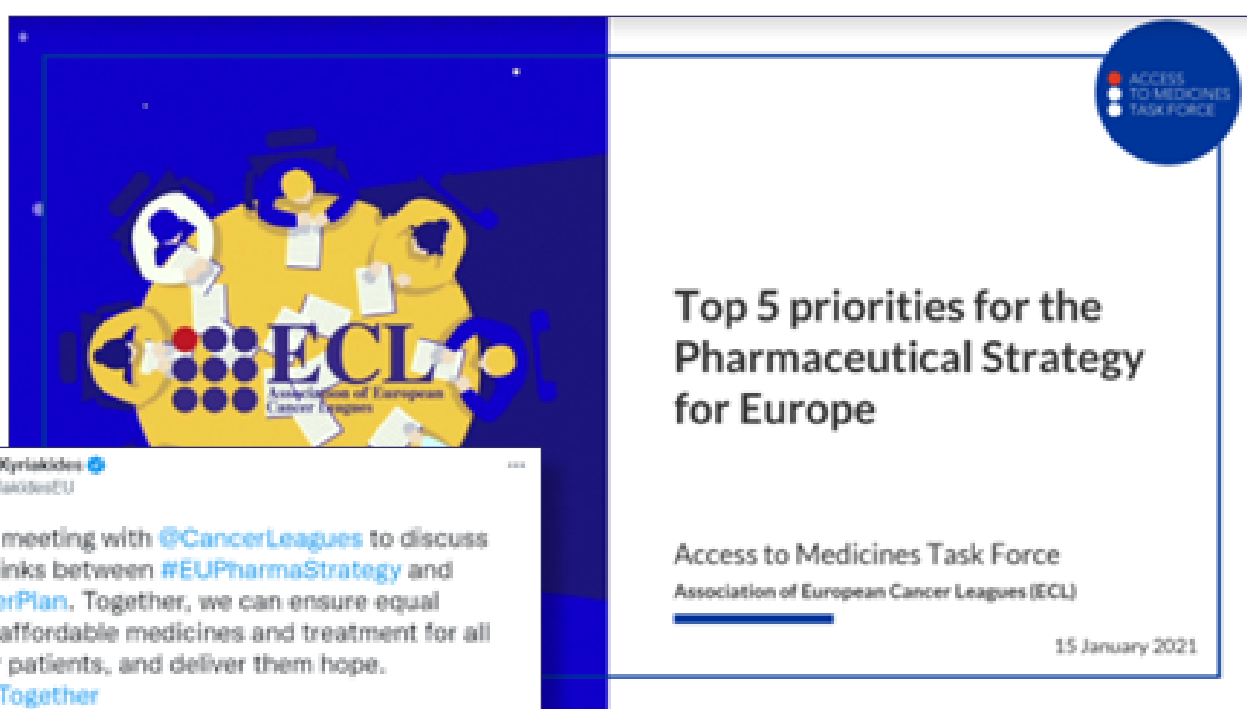
1. Get busy on social media creating your own content and sharing [our material](#).
2. Hold [online meetings/webinars](#) with your partners, collaborators and members to inform them about the actions within [Europe's Beating Cancer Plan](#).
3. Participate in other ECL's activities:
 - [policy dialogue on medicines for children and rare diseases](#)
 - [webinar on the GDPR and clinical research](#)
 - [webinar on physical activity](#)
 - [joint statement on cervical cancer elimination](#)
 - [virtual artistic exhibition](#)

21 January 2021

Virtual meeting with EU Commissioner Stella Kyriakides

The ECL Secretariat and the Steering Committee of the ECL Access to Medicines Task Force had the pleasure to e-meet Stella Kyriakides, the European Commissioner for Health and Food Safety, and her team to present cancer leagues' top 5 priorities for the Pharmaceutical Strategy for Europe and discuss the implementation of Europe's Beating Cancer Plan.

Steering Committee members presented the Task Force's views of fair prices and fair pricing, cross border collaboration and joint procurement, orphan and paediatric medicines and medicine shortages.



9-10 November 2020

ECL 40th Annual Meetings

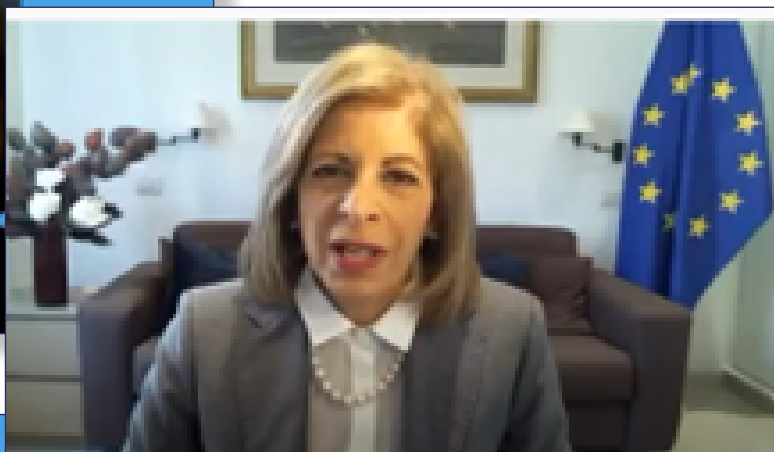
The ECL's annual conference and general assembly and meetings were exceptionally held online due to the COVID-19 pandemic.

ECL celebrated its 40th birthday in the good (virtual) company of members and long-time supporters, including European Commission officials, current and former MEPs, and our civil society partners.

ECL's 2020 annual conference was held online and exceptionally opened to all stakeholders to celebrate its 40th anniversary of service to cancer societies across Europe, the winner of the first ever ECL Honorary Award as well as the countdown to the announcement of Europe's Beating Cancer Plan.

The conference put a spotlight on the 40th anniversary of ECL and the future of cancer prevention and control in view of the launch of Europe's Beating Cancer Plan and the Horizon Europe's Mission on Cancer.

At the virtual General Assembly, a new President and Board member were elected.





9-10 November 2020

8th European Conference on Tobacco or Health (ECToH)

The European Conferences on Tobacco or Health (ECToH) are held every three years and unites over 600 influential advocates, researchers, academics, non-governmental organisations, civil society, scientists, healthcare professionals and public officials working on all aspects of tobacco control from around Europe.

The 8th ECToH was held in 2020 in Berlin and hosted by the German Cancer Society. Key messages from the Conference were published in the Berlin Declaration.

Check out the ECToH 2020 official website: <https://www.ectoh.org/> and read the ECToH Round Up.

At the Closing Ceremony, it was announced that the next ECToH will take place in 2023 in Madrid and will be hosted by the Spanish Association Against Cancer!

Last, but by no means least, ECL Tobacco Control Advocacy Officer - Luk Joossens - was presented with a Special Award during ECToH 2020 to mark his retirement from ECL and his exceptional contribution as one of world's foremost tobacco control advocates in a career spanning over 40 years.



ECL PATIENT SUPPORT WORKING GROUP

Since 2007 the ECL Patient Support Working Group (PSWG) connects cancer care experts within cancer leagues who work together on issues such as access to insurance and financial services, return to work, caregiver support, cancer rehabilitation and palliative care. PSWG members share best practices, develop guides and other informational materials to raise awareness of and improve patient care. The PSWG also seeks to ensure the patient voice is heard in both national and European policy-making.

ECL PSWG was chaired by Alrik Meesen (Dutch Cancer Society) and by Vice-Chair Monick Leal (Portuguese League Against Cancer) from November 2018 until April 2021. Monick Leal was subsequently elected the new Chair in October 2021; whereas the Vice-Chair position remained vacant.

2021 work themes & outputs

Promotion of cancer rehabilitation programmes and activities used by cancer leagues

- **May 2021** - Rehabilitation Atlas (2nd edition) - an inventory of 61 different rehabilitation programmes and activities supporting the physical and psycho-social rehabilitation of patients and caregivers

Improved communication between employers and employees affected by cancer volunteer

- **November 2021** - Leaflets for employers and employees with cancer on how to manage cancer at the workplace.

2020 work themes & outputs

Improved communication between cancer patients and healthcare professionals (HCPs)

- **September 2020** - Leaflets for patients and healthcare professionals on how to break the taboo and start much needed conversations about cancer, sexuality and intimacy

Improved communication between employers and employees affected by cancer volunteer

- **November 2020** - Handbook for employers, HR professionals and businesses on how to manage cancer at the workplace

Meetings

- 16 February 2021, online
- 12 October 2021, online
- 31 March 2020, online
- 15 September 2020, online

Find here all the publications of the PSWG



ECL ACCESS TO MEDICINES TASK

Established in 2016, the ECL Access to Medicines Task Force (A2M TF) aims to ensure that safe and effective medicines and treatment are available to all cancer patients in Europe by advocating for increased accessibility, affordability and transparency of medicine prices, ultimately leading to sustainability of healthcare systems. The Task Force strongly believes in the power of constructive dialogue and urges all stakeholders to push for greater accessibility to high quality treatments, improving both survival and the quality of life of cancer patients.

2020-21 Key outputs

Affordability, transparency & accessibility

- **December 2021** - Policy paper on cross border collaboration initiatives in the healthcare space
- **May 2021** - Joint recommendations for improving the 2000 Orphan Regulation and the 2006 Paediatric EU Regulations
- **May 2021** - active participation and statement about the WHO Fair Pricing Forum
- **August 2020** - Position paper on cancer leagues' vision for the EU Pharmaceutical Strategy

- **September 2020** - Policy paper on fair prices and fair pricing policies

External events

- **December 2021** - Virtual launch of the policy paper on cross border collaboration initiative and fair medicine deals
- **May 2021** - Joint policy dialogue on the Revision of the EU Regulations on Medicines for Children and Rare Diseases
- **September 2020** - Virtual launch of the 'What is a Fair Price?' position paper
- **November 2020** - Virtual launch of the European Fair Pricing Network (EFPN)

Meetings

- 15 March 2021, online
- 21 October 2021, online
- 19 March 2020, online
- 29 October 2020, online

Find here all the publications of the A2L TF



MEPS AGAINST CANCER INTEREST GROUP

ECL is proud to provide the Secretariat for the MEPs Against Cancer (MAC) Interest Group at the European Parliament since 2010.

With the establishment of the Challenge Cancer Intergroup and the Special Committee on Beating Cancer, the MAC Interest Group remained the oldest and largest group dedicated to oncopolicy at the European Parliament in 2020-21.

MAC members come from different political groups and countries and work together to strengthen cancer control policies, promote cancer prevention, ensure access to high quality treatments and care for cancer patients in Europe. MAC members strongly believe that European cooperation adds value to Member States' action.

In 2021, the group counted 123 members - two members less than 2020, as a Croatian and Romanian MEP left the European Parliament to take over new jobs.

When the UK left the EU on 31 January 2020, the 73 UK members of the European Parliament (including 12 MAC members) vacated their seats in Brussels and Strasbourg. The two elected Co-chairs, MEP Petra De Sutter (Greens/EFA, Belgium) and MEP Miriam Dalli (S&D, Malta) accepted new roles in their respective national governments and were replaced by MEP Tilly Metz (Greens/EFA, Luxembourg) and Sara Cerdas (S&D, Portugal).

2021-21 Campaigns

- **World Cancer Day** - 4 February
- **European Week Against Cancer** - 25-31 May

2021 Meetings

- **6 Individual meetings** and engagement with MEPs and their Assistants to present the views of cancer leagues
- **2 policy dialogues:**
 - Joint policy dialogue on cervical cancer elimination, 5 February
 - Joint policy dialogue on cross border collaboration in the healthcare space, 9 December
- **2 stakeholders' events:**
 - Joint iPAAC WP8 and WP10 stakeholders' event on cancer care governance in the EU, 15 March
 - MAC & SFP stakeholders' event on the Tobacco Products Directive, 29 June
- **2 associated events:**
 - MAC & ESMO associated event on the impact of GDPR on cancer research, 21 May
 - MAC, SIOPE, CCI Europe & Pancare associated event on childhood cancer, 30 September
 - 1 internal Meeting for MEPs and assistants to discuss the action plan and functioning of the interest group in 2021, 30 November

2020 Meetings

- **17 Individual meetings** and engagement with MEPs and their Assistants to present the views of cancer leagues and recruit them to become members of MAC for the legislature 2019-2024





- Supported the launch **event of the Europe's Beating Cancer Plan Consultation** to mark World Cancer Day, Brussels, 4 February 2020
- **1 MAC, SIOPE, CCI Europe & Pancare stakeholders'** event, 8 September
- **1 internal meeting** for MAC members and their parliamentary assistants, 1 December

Learn more about MAC

CANCER PREVENTION



EUROPEAN CODE AGAINST CANCER (ECAC)

The European Code Against Cancer (ECAC) is an initiative of the European Commission, developed by the World Health Organization's International Agency for Research on Cancer (IARC). The ECAC aims to inform people about actions they can take for themselves or their families to reduce their risk of cancer. Leading cancer scientists from across Europe compiled the ECAC based on the latest scientific evidence on cancer prevention, coming up with twelve recommendations that most people can follow without any special skills or advice. It has been estimated that almost half of all deaths due to cancer in Europe could be avoided if everyone followed the recommendations.

2020-21 Key outputs & achievements

Tools

Cooperated with IARC on the development of e-learning modules to promote better understanding of the evidence supporting the ECAC and new evidence emerged since the launch of the 4th edition of the ECAC, run and administered by IARC (via Cancer Prevention Europe). The first set of modules was launched on 16 April 2021 and the second set on 11 November 2021.

Launch of the WASABY educational mobile app to help young people learn the messages within the ECAC, February 2021

Launch of the interactive map of the ECAC, which can be used to explore national efforts of EU member states against each message within the ECAC, February 2020

Joint infographics and social media fact cards on environmental pollutants and cancer prevention developed with HEAL, May 2020

Reports

Cancer leagues' viewpoint on the next updated of the ECAC to a 5th edition, November 2021

Policy framework based on the ECAC outlining the supportive governmental actions needed for implementation of ECAC at national and European levels, March 2020

7th Tobacco Control Scale quantifying the implementation of tobacco control policies at country level in 2019 and is based on tobacco control policies described by the World Bank, launched on 20 February 2020

Evaluation report on the impact of the ECAC awareness and attitudes towards cancer prevention in collaboration with IARC, November 2020





Articles, letters & statements

- **Article** - Sustainability and monitoring of the European Code Against Cancer: Recommendations, June 2021
- **Article** - Evaluation of the impact of the European Code against Cancer on awareness and attitudes towards cancer prevention at the population and health promoters' levels, April 2021
- **Open letter** to European Commissioners Wojciechowski and Kyriakides regarding the Common Agricultural Policy, September 2020
- **Open letter** to European Commissioner Kyriakides regarding the European Chemicals Strategy for Sustainability, September 2020
- **Endorsement** of the European Whole

Grain Advocacy (EWGA)'s statement, May 2020

- **Letter of support** for the continuous updated of the European Code against Cancer, May 2020

2020-21 key events

- Coordinated the organisation and implementation of the **8th European Conference on Tobacco or Health (ECToH)** in Berlin alongside the launch of the Tobacco Control Scale and the German Cancer Congress. The conference attracted 309 participants from 44 countries.
- Internal launch of the **WASABY mobile app** based on the messages of the ECAC, December 2020

YOUTH AMBASSADORS FOR THE ECAC

The ECL Youth Ambassadors (YAs) programme is the only European-wide youth-led network of advocates for cancer prevention. The programme was funded in 2012 within the European Partnership Action Against Cancer (EPAAC) to connect young Europeans who share a common mission: reducing the devastating burden of cancer by promoting healthy lifestyle choices known to reduce cancer risks. YAs make creative and enterprising actions to promote and disseminate the ECAC in their countries of residence, and participate in joint cancer awareness campaigns. YAs receive training, financial resources and secretarial support from ECL, which aims to nurture them to become successful leaders in cancer control and the wider EU health community.

The ECL YAs for the ECAC programme continued to develop positively during 2020-21. The programme consisted of 68 people from 39 different countries in the wider European region. For ECL, an added benefit is the ability to reach

countries in the European region that do not yet have a cancer league eligible to join ECL, thereby extending our geographical scope. Annual calls for applications were launched in January 2020 and 2021. As a result, ECL respectively recruited 11 and 15 new Ambassadors.

Following a mid-term evaluation of the programme, a work stream method was implemented in September 2020. The four chosen work streams were: advocacy, digital communication, events & education, and research.

Actions

- 80 individual and joint actions in 2021
- 136 individual and joint actions in 2020

Report & Letter

- **Letter to the editor:** Youth Ambassadors for the European Code Against Cancer Initiative - a call to action, November 2020
- **Mid-term evaluation** of the programme, July 2020

2020-21 Events

- ECL, IARC & UNC webinar on physical activity and cancer, May 2021
- ECL, IARC & WHO/Europe webinar on alcohol and cancer, November 2021
- Digital Summer School, 23-27 August 2021
- ECL, HEAL & ETUI webinar on

occupational health and cancer, February 2020

- ECL & EUROSIN webinar on sun safety, May 2020
- ECL, ILO & My PeBS Webinar on breast cancer, October 2020
- Digital summer school, 27-28 August 2020

Watch ECL webinars





CANCER PREVENTION & EARLY DETECTION WORKING GROUP

Following a consensus statement produced as part of a cancer prevention study visit in 2019, a new ECL Prevention and Early Detection Working Group (P&EDWG) was constituted as a standing entity within ECL in June 2020. The working group aims to build on the extensive work and experience regained from the past 5 years' of promoting the 4th edition of the European Code against Cancer, focusing on three main thematic areas, namely early detection, obesity and tobacco control.

In 2020, a total 75 representatives covering all member leagues joined the working group. The first Chair of the group was elected in October 2020: Cristiana Fonseca from the Portuguese League against Cancer. ECL Board member Darina Sedlakova was appointed the Vice-Chair. In 2021, subgroup leaders for each of the three thematic areas were appointed by the ECL Secretariat.

2020-21 work themes & outputs

Early Detection

Subgroup leaders: Urska Ivanuš (Association of Slovenian Cancer Societies) and Mathijs Goossens (Belgian Foundation Against Cancer) until December 2021, replaced by Janne Villemoes Bigaard (Danish Cancer Society).

Teleconferences: 22 June and 23 November 2021

Output: A three-step survey to identify tools and practices to inform the general public about

screening and to promote uptake of screening.

Obesity

Subgroup leader: Birna Þórisdóttir (Icelandic Cancer Society) until October 2021, replaced by Gitte Laub Hansen (Danish Cancer Society) from December 2021

Teleconferences: 23 March and 22 June 2021

Output: Mapping of members' experience in the field of obesity, overweight and cancer to identify areas of common interest for future actions.

Tobacco control

Subgroup leaders: Daniela Giangreco (LILT) and Eeva Ollila (Cancer Society of Finland)

Teleconferences: 23 March and 22 November 2021

Outputs: Joint policy dialogue and recommendations on the Tobacco products Directive and contributions towards the next ECToH conference to be held in Madrid in 2023.

Plenary Meetings

- 23 June 2021, online
- 30 June 2020, preliminary meeting, online
- 21 October 2020, constitutive meeting, online
- 9 December 2020, online

CERVICAL CANCER ELIMINATION

Event

- Joint policy dialogue on cervical cancer elimination, 5 February 2021

Articles, statements and reports

- Joint statement - Priorities for eliminating cervical cancer as a public health problem in Europe, July 2021
- Infographic - Priorities for eliminating cervical

cancer as a public health problem in Europe, July 2021

- Open letter to members of the WHO Regional Committee for Europe ahead of the 70th session, September 2020
- Special Report - The European response to the WHO call to eliminate cervical cancer as a public health problem, July 2020
- Correspondence - Tackling cervical cancer in Europe amidst the COVID-19 pandemic, July 2020

CERVICAL CANCER ELIMINATION

Proposals

ECL contributed to the submission of a proposal for an action grant under the new EU4Health programme for the CanScreen-ECIS project, which aims to develop and pilot a new screening data management system to be integrated to the European Cancer Information System (ECIS) in September 2021.

Following a meeting of the co-authors of the 2nd EU cancer screening report in October 2019, ECL joined a draft proposal in 2020 with the co-authors of the report towards a 3rd EU cancer screening report to support the long-term development of cancer screening monitoring and evaluation in Europe, and a permanent platform for exchange between competent bodies for screening.

Articles & statements

- Summary document on lung cancer screening, (not publicly available)
- Mini Review - Key issues that need to be considered while revising the current annex of the European Council Recommendation (2003)

on cancer screening, January 2020

- Consensus Statement - Personalized early detection and prevention of breast cancer: ENVISION consensus statement, June 2020

2020-21 Key events

- ECL's third screening workshop focusing on the key considerations to update the of the Council recommendation of 2 December 2003 on cancer screening took place in November 2021.
- ECL's second screening workshop dedicated to the topic of informed decision making in cancer screening which took place in December 2020.
- ECL organised an online meeting on 23 June 2020 with European Commission and cancer screening experts (including IARC, CPO Piemonte, Finnish Cancer Registry, JRC, Erasmus MC, Sciensano) to discuss future of cancer screening monitoring in Europe.
- A special webinar was organised for member leagues on 17 July 2020 with CPO Piemonte and IARC to discuss the issue of restarting cancer screening in the aftermath of the lockdowns imposed due to Covid-19.





EU-FUNDED PROJECTS



CBIG-Screen

ECL is an associated partner in the Horizon 2020 project CBIG-SCREEN. The project launched in March 2021. ECL is a leading partner in the communication and dissemination work package and deputy leader of the work package on stakeholder engagement. [Learn more](#)



MyPeBS

ECL is an associated partner in the Horizon 2020 project MyPeBS (My Personal Breast Screening). ECL is task leader in the work package on communication focusing on communication to the general public. In 2019, the Secretariat regularly communicated about the project's status and milestones through newsletters and update emails. ECL has facilitated contact between the project partners and ECL member leading to special briefings for member leagues to inform them about the project. A social media campaign to draw attention to the project was organised during Pink October 2021. [Learn more.](#)



Wasaby

ECL is an associated partner in the pilot preparatory action WASABY (Water and Soil contamination and Breast Cancer risk in Young Women). ECL leads the work package on dissemination. In 2020, the ECL Secretariat developed the WASABY mobile application, an educational app to help young people learn the messages within the European Code Against Cancer and how to lead a healthy life whilst reducing their cancer risk.

The app was launched on 4 February 2021 to mark World Cancer Day. The app can now be downloaded on the Google Play store and App store. The app is made up of 10 content modules and quizzes. Reward badges are unlocked at the end of each module and real-time data on progress is registered to create an international ranking list of the top learners around Europe. The project concluded in June 2021 and a manuscript of the methodology to develop the app will be submitted for publication. [Learn more](#)

EU JOINT ACTIONS



EU-JAV

The European Joint Action on Vaccination (EU-JAV) started in 2018 and will end in spring 2022 bringing together the European Commission, health ministries, international policymakers and organisations, institutes, universities from 20 countries and a wide range of stakeholders working on vaccination policy and health services.

ECL is subcontracted by the French Ministry of Solidarity and Health to help develop a strategy to communicate vaccination to young people, capitalising on experiences in previous Joint

- Actions. In 2021, ECL organised a Europe-wide school competition on the importance of HPV vaccination targeting young people under 26 years old. ECL received a total of 85 submissions from 21 countries. 1 panel of 5 expert judges of different backgrounds scored the short-listed entries based on 4 criteria and selected the 8
- winners, who received prizes and visibility for their entries.



iPACC

The Innovative Partnership for Action Against Cancer (iPAAC) Joint Action started in 2018 and ended in December 2021 bringing together 24 Associated Partners (with Affiliated Entities, 44 partners) across Europe whose main objectives are to build upon deliverables of the CANCON Joint Action and to implement innovative approaches to cancer control. A Roadmap on Implementation and Sustainability of Cancer Control Actions was the main deliverable of this Joint Action.

- ECL was subcontracted by the Cancer Society of
- Finland to support the organisation of 2 online meetings of work package 5 on cancer prevention in 2020. ECL supported the dissemination efforts of Work Package 8 and 10 and co-organised an online event on 15 March 2021. ECL also supported the planning, organisation and implementation of the final hybrid conference of the joint action on 13-14 December 2021.





ECL MEMBERS

ECL is committed to growing and nurturing a strong network of members and partners, fostering knowledge-sharing and empowering cancer leagues.

ECL exists for and because of our members, and the amazing work they do to fight cancer on all fronts is what drives us to keep trying to support their needs and influence policy on their behalf. We are proud to represent cancer leagues at the EU level and we will keep working hard to make beating cancer a mission possible.

ECL members are cancer societies operating across the whole cancer continuum and patient pathway - from cancer research and awareness to patient support during and after diagnosis. Cancer leagues are the main resource for the public for cancer control information and services. From Iceland to Cyprus, cancer leagues contribute to preventing and fighting cancer by, amongst

other things, raising awareness and educating people about cancer, investing in research and providing support to cancer patients and their families during and after treatment.

In 2020-21, our member leagues together employed more than 8,000 staff and 1,100,000 volunteers, and represented over 570,000,000 citizens. They raised and spent approximately €700,000,000 for cancer research.

In 2020, ECL welcomed one new member - the Croatian League Against Cancer - for a total of 30 members from 25 countries in the WHO European Region, covering 20 EU member states. The Croatian League Against Cancer became a member following the virtual Annual General Assembly in November 2020. To mark this milestone, an updated Members' Booklet was launched at the 2020 General Assembly.



FINANCIAL REPORTS

ECL was proudly co-financed by the Health Programme of the European Union. ECL was awarded annual operating grants through the Third Health Programme (2014-2020) from 2015 until 2021. ECL was in regular contact with Garnier International, who is providing ECL with an annual unrestricted educational grant as part of the current contract for 2019-2021.

ECL accepts industry contributions only in the form of unrestricted educational grants for specific projects and activities at the discretion of the ECL Executive Board, and on the condition that companies cannot influence how the funding is used by ECL. Additionally, such contributions are never applied to core operating costs. We do not accept any support from the tobacco industry, or any other companies who produce products that are deemed harmful to health.

ECL has a transparent accounting policy. ECL accounts are reviewed by an independent auditor on a yearly basis and are available upon request. The ECL auditor's report, budget, income, and expenditure are submitted each year for approval by our members at the extraordinary general assembly in June and at the regular annual general assembly in November. Our finances are publicly available in our Annual Reports, which are disseminated to all members and published online on our website.

Income sources 2021

In 2021, ECL's total operating income was EUR 659.899.

The operational budget is devoted to our core activities to improve cancer control and care and strengthen the voice of national and regional cancer leagues across Europe.

Our biggest financial contributor is the Operating Grant received from the European Commission.

In 2021 its contribution represented about 48% of ECL's total Operating Income. The total contribution from membership fees represented about 33% of the Operating Income. In addition to the operational budget, ECL is a partner in several EU-funded projects.

ECL accepts industry contributions only in the form of unrestricted educational grants, and on the condition that companies cannot influence how the funding is used by ECL. Additionally, such contributions are never applied to core operating costs

Income sources 2020

In 2020, ECL's total Operating Income was EUR 407,023.41.

The operational budget is devoted to our core activities to improve cancer control and care and strengthen the voice of national and regional cancer leagues across Europe.

Our biggest financial contributor was the Operating Grant received from the European Commission (n: 785273) under the Third Health Programme. In 2020, its contribution represented about 45% of ECL's total Operating Income.

In 2020, the total contribution from membership fees represented about 33% of the Operating Income. In addition to the operational budget, ECL was a partner in two EU-funded health research projects (WASABY and MyPeBs).

An unrestricted educational grant from Garnier International represented the remainder of our income.



FINANCIAL REPORT



Registered Auditors

Koninkrijksweg 24 • B-1031 Brussels

Association of European Cancer Leagues ASBL
Chaussée de Louvain 479
1030 Brussels

AUDITOR'S REPORT FOR THE FINANCIAL YEAR STARTED ON THE 1ST JANUARY 2018 AND ENDED ON THE 31ST DECEMBER 2018 OF THE ASSOCIATION OF EUROPEAN CANCER LEAGUES (ECL) (RPR 0867.170.595)

Objective and scope of the review

Upon the request of the Director, we have reviewed the accompanying financial statements of the ASSOCIATION OF EUROPEAN CANCER LEAGUES (ECL) as at December 31st, 2018. The Board of Directors of ECL is responsible for the preparation of this financial information in accordance with the Belgian generally accepted accounting principles. These statements indicate a balance sheet total of € 811,899.56 as well as revenues in excess of expenses of € 8,526.03.

We conducted our review in accordance with the legal requirements and the Auditing Standards applicable in Belgium, as issued by the Institute of Registered Auditors (*Institut des Réviseurs d'Entreprises / Instituut van de Bedrijfsrevisoren*) and, more particularly, in accordance with its Standards in regards to a limited review.

This review, in accordance with the aforementioned standards, consists principally of applying analytical procedures to financial data and making inquiries of persons responsible for financial and accounting matters.

A limited review is substantially less in scope than an audit, the objective of which is the expression of an opinion regarding the financial statements. Accordingly, we do not express an audit opinion. A limited review does not provide assurance that we would become aware of any or all significant matters that might be identified in an audit.

Review

We have obtained from the management and responsible officers of the Association all of the explanations and information necessary for our review. We believe that the evidence we have obtained in our review is sufficient and appropriate to provide a basis for our conclusion.

In our opinion, the financial statements as of December 31st, 2018, were established in accordance with the financial reporting framework applicable in Belgium and the accounting records were maintained with the legal and regulatory requirements applicable in Belgium.

FINANCIAL REPORT



2

The current revenues amount to € 554.378,38 and the expenses amount to € 545.850,36 and hence, the financial statement as at 31st December 2018 indicates revenues in excess of expenses of € 8.528,03.

After thorough examination and analysis of the available documents and data, we can confirm that operating costs were sufficiently justified by supporting documents.

Additional information

The compliance by the Association with the law of 27 June 1921 related to not-for-profit associations, international not-for-profit associations and Associations is the responsibility of management.

Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.

There are no transactions undertaken or decisions taken in violation of the Associations by-laws or the law of 27 June 1921 related to not-for-profit associations, international not-for-profit associations and Associations that we have to report to you.

Conclusion

We have reviewed the accompanying financial statements of the ASSOCIATION OF EUROPEAN CANCER LEAGUES (ECL) as at 31st of December 2018, prepared by its Board of Directors, indicating a balance sheet total of € 911.889,58 and revenues in excess of expenses of € 8.528,03.

Based on our reviews, nothing has come to our attention that causes us to believe that the financial statements are not prepared, in all material respect, in accordance with the Belgian generally accepted accounting principles.

Zellik, 6th of March 2019

Lutijn, Sanghini & Co Registered Auditors BVBA
represented by Saskia Lutijn



MEMBERSHIP OVERVIEW FOR 2021



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[@cancerleagues](https://www.facebook.com/cancerleagues)

Foundation Against Cancer Belgium
Stand Up To Cancer Flanders
Cyprus Anti-Cancer Society
Cyprus Association of Cancer Patients and Friends
League Against Cancer Prague
Danish Cancer Society
Faroese Cancer Society
Cancer Society of Finland
French League Against Cancer
German Cancer Society
Hungarian League Against Cancer
Icelandic Cancer Society
Irish Cancer Society
Israel Cancer Association
Italian Cancer League
Cancer Foundation Luxembourg
Dutch Cancer Society
Polish Cancer League
Portuguese League Against Cancer
Romanian Cancer Society
League Against Cancer Slovakia
Association of Slovenian Cancer Societies
Swiss Cancer League
Catalan Federation Against Cancer
Turkish Association for Cancer Research and Control
Cancer Focus Northern Ireland

