

Annual Report 2019

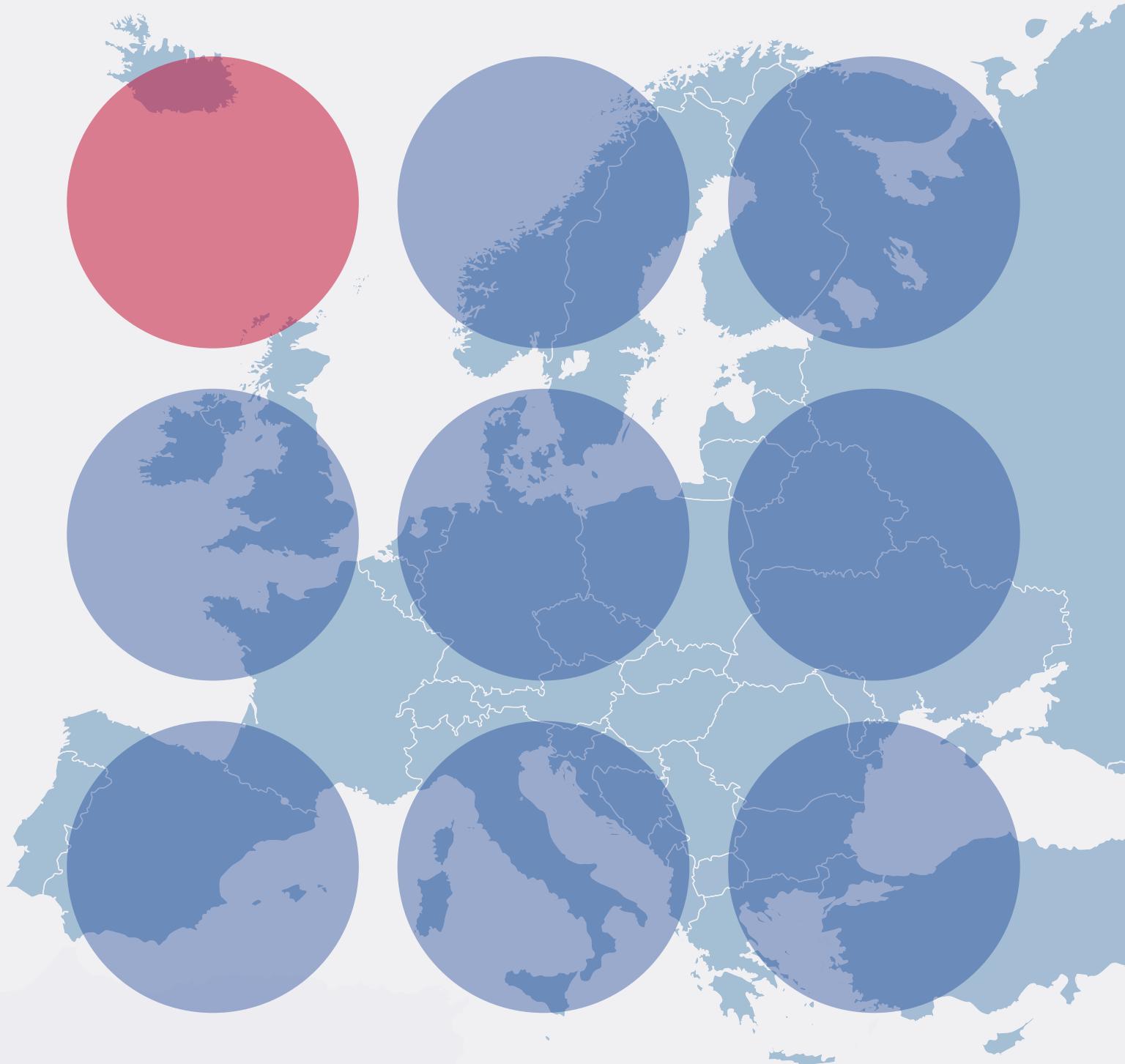


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MESSAGE FROM THE PRESIDENT

This was a great year for ECL, working with the European community across our key thematic areas: cancer prevention, tobacco control, access to medicines and patient support. Being an EU election year, it represented a turning point in so many ways. The European elections concerned us all - especially our members and the citizens, patients, survivors and caregivers we serve. The new President of the European Commission, Ursula von der Leyen, and the new European Commissioner for Health and Food Safety, Stella Kyriakides, are both seasoned public health promoters with personal cancer stories. They both recognise that the fight against cancer is a field where European cooperation, pooling of data and resources can make a real difference in the lives of millions of Europeans. This will surely strengthen ECL's good relationship with the European Commission, members of the European Parliament and European civil society organisations further. It will also facilitate dialogue with the European institutions over the coming years. Cancer leagues will take advantage of this strong momentum in the EU oncopolicy landscape to put a spotlight on their long-held messages around the need to (i) implement governmental policies and actions supporting the messages of the European Code Against Cancer, (ii) enhance access to scientifically proven effective and quality controlled cancer screening programmes, (iii) ensure equal access to high-value cancer treatments for cancer patients, (iv) improve support services and care for cancer patients, survivors and caregivers and (V) address inequalities and ensuring that 'no one is left behind'.

We now have 29 member leagues in 24 countries. I would like to thank all our members, especially those leading and actively participating in the Patient Support Working Group and the Access to Medicines Task Force for their hard work and outputs.

In November 2019, the Foundation Cancer Luxembourg hosted the ECL meetings and Annual Conference in Luxembourg City. These events were professionally organised and the host succeeded in creating an excellent environment for discussion between the member leagues. The General Assembly saw the election of two new Board Members, Dr Lucienne Thommes, Director of the Foundation Cancer Luxembourg, and Dr Darina Sedláková, who sits on the Board of the Slovak League Against Cancer. I would like to extend my warmest thanks to the hard-working ECL Board Members and to the proactive and professional 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, the excellent work our staff is doing and the Board Members representing ECL in various important events.



Sakari Karjalainen
ECL President

ECL EXECUTIVE BOARD

The 2019 Executive Board comprised of the following members:



Sakari Karjalainen - President
Cancer Society of Finland



Rui Medeiros - Vice President
Portuguese League against Cancer



Roisin Foster - Treasurer
Cancer Focus Northern Ireland
(until November 2019)



Elizabeth Hjorth - Legal Counsel
Danish Cancer Society



Jacqueline Godet
French League Against Cancer
(until June 2019)



Nicolas Philippou
Cyprus Association of Cancer
Patients and Friends





ECL Board Activities

Following the statutes and by-laws stipulating that the Board should meet at least 4 times a year, the ECL Executive Board met 5 times in 2019 between the General Assembly of 2018 in Berlin and the General Assembly (GA) 2019 in Luxembourg: in Berlin on 16 November, in Cyprus on 11-12 March, in Paris on 28-29 May, in Copenhagen on 3-4 October and in Luxembourg City on 27 and 29 November (next to the GA). In addition to meetings and teleconferences, there were regular email correspondences and meetings at cancer conferences and events between Board members, especially the President, Vice-President and Treasurer, and the Secretariat.

Notable agenda items for Board meetings this year included the monitoring of activities being implemented and deliverables of the EU Operating Grant as well as ECL's participation in Joint Actions (The Innovative Partnership for Action Against Cancer (iPAAC) and the European Joint Action on Vaccination (EU-JAV). The Board made an evaluation on the membership fee model. A very important issue for the Board members was the impending retirement of ECL's long-time Tobacco Control Advocacy Officer, Luk Joossens after the European Conference on Tobacco or Health (ECToH) 2020.

Other discussion points were organising the 2020 Annual Meetings, the creation of an ECL Honorary Award, the approval of 3 new members (Spanish Association Against Cancer, Cancer Research UK, and O Fonds of Latvia), exploring potential members, formulating the ECL Research Survey for mapping cancer research among the leagues, commissioning an external evaluation in response to the EU Operating Grant recommendations, preparing for the establishment of a new working group on cancer prevention and early detection, and reviewing staffing needs for the Secretariat office in Brussels.

Overall, 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 a remuneration for their roles. **ECL is grateful for their support, dedication, and active contributions to the work of ECL throughout the year, as well as for their valuable advice in guiding the Secretariat in its activities.**



As **President, Sakari Karjalainen** was in regular contact with the Secretariat staff in Brussels, in particular with the Director who reports directly to him. As President of the Board, he oversaw the activities of the office in Brussels and chaired all Board meetings and teleconferences. He provided advice to the Secretariat on interacting with industry. Externally, Sakari was the official ECL representative in the European CanCer Organisation (ECCO) where ECL has been a member since 2016. Sakari spoke on behalf of the ECL at external meetings, such as those at the European Parliament and at the MEPs Against Cancer (MAC) roundtables for which ECL provides the Secretariat. He sat on the Scientific Committee for the European Conference on Tobacco or Health (ECToH) in February 2020 and participated in reviewing sessions and abstracts. Sakari travelled to Latvia for introductory meetings with the cancer league O Fonds and cemented a good collaboration where they are now a member. As the leader for the Work Package on Prevention in the Joint Action for Innovative Partnership Action Against Cancer (iPAAC), Sakari has facilitated the involvement of ECL as a subcontractor of his league - the Cancer Society of Finland - in this Joint Action. Along with Elizabeth Hjorth, he was the Board contact for the Nordic Cancer Union (NCU).



Rui Medeiros, as **Vice-President**, worked closely with the President and stepped in when possible when the President was not available. He represented the President in meetings with the European Cancer Organisation (ECCO), as well as in their summit in September. As a clinician and researcher, Rui helped ECL provide feedback into papers ECL receives for comments, especially related to cervical cancer. His league, the Portuguese League is very active in the area of primary prevention, so he has encouraged his league to support ECL's work at the European level in areas such as tobacco control and skin cancer prevention. His league continued to be vital in providing advice and resources to ECL's work for the European Code Against Cancer due to their many successful campaigns.



Rosin Foster, as **ECL Treasurer**, was responsible for the finances of the Association, working closely with the ECL Accountant and Auditor. She monitored the financial situation of ECL and discussed financial and administrative issues with the other Board members and with the new Operations Coordinator. She provided advice to the Secretariat when required regarding the relationship with the Auditor and Treasurer. Roisin provided an update on the financial status of ECL at each Board meeting and ensured that ECL's balance sheet was healthy. She was also the Board Contact for the Patient Support Working Group.



Elizabeth Hjorth, the **legal counsel** for the Board and ECL, has been providing valuable legal and administrative advice to ECL when issues arise. Based on her extensive experience at the Danish Cancer Society and negotiating in partnerships, Elizabeth has also been providing advice to ECL on staying independent of industry influences and has been instrumental in

connecting relevant colleagues in specific areas of work with ECL, such as in prevention related to the European Code Against Cancer and the Access to Medicines Task Force. Along with Sakari, she is the Board contact for the Nordic Cancer Union and is an important link with the Nordic countries. Elizabeth kindly hosted the Board meeting in October.



Jacqueline Godet involved ECL in the French League's International Inter-Commission Committee (ICI) to allow ECL's input into the French League's international affairs, which includes a wide range of issues including tobacco control and access to medicines. She helped give visibility to the ECL Youth Ambassadors' (YA) Group by inviting one of the YAs to be part of the ICI. She hosted the Board meeting in May, as a farewell right before her retirement from the French League. Jacqueline paved the way for a strong collaboration between ECL and its French member.



Nicolas Philippou was the Board contact for the area of **Access to Medicines** and also provided guidance on issues related to **patient support**. Nicolas brought in his experience as an alumnus of the European Patients' Academy (EUPATI), a member of the Patient Advocacy Working Group at the European Society for Medical Oncology (ESMO), and a member of the audit committee at the European Cancer Patient Coalition (ECPC). Given his experience and large network among patient advocates, Nicolas ensured the patient voice is present in all activities ECL undertakes. Nicolas kindly hosted the Board meeting in March and organised an important political Press Conference with the participation of candidates for the European Parliament as well as the EU Commissioner-designate for health and food safety. This strategically timed event before the European elections gave ECL much visibility and connections to the current Cypriot MEPs.





ECL SECRETARIAT

The vision of the Association of European Cancer Leagues (ECL) is for a Europe Free of Cancers. 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, tobacco control, access to medicines and patient support, as well as creating opportunities to advocate for these issues at the EU level. ECL also collaborates with global and European institutions, other NGOs and research institutes.

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 new ECL Strategy 2019-2021, and the commitments taken under the Operating Grant for the period 2018-2021.**

ECL Secretariat staff

The core staffing at the ECL Secretariat in Brussels in 2019:

Wendy Yared, Director, at 100%

David Ritchie, Senior Cancer Control Officer, at 100%

Anna Prokůpková, Policy and Project Officer, at 100%

Luk Joossens, Tobacco Control Advocacy Officer, at 20%

Elisabeth Dupont, Operations Coordinator at 75%, until September 2019

Anne Revell, Office Manager at 25-50%, from September 2019

Additionally in 2019:

Ginevra Papi, EU Solidarity Corps Trainee, March 2019 - December 2019

Meritxell Mallafré-Larrosa, Research Associate (formerly EU Solidarity Corps Trainee), freelance

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 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 pushing for increased accessibility, transparency of medicines prices and sustainability of the healthcare system.

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 Secretariat Activities

Convening

Events

ECL was active in varying capacities, as (co-)organisers, speakers, or committee member in more than 60 events in 2019.

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 umbrella organisations to strengthen collaboration and avoid duplication of efforts, notably with IARC (WHO's International Agency for Research on Cancer), Cancer Prevention Europe (CPE, of which ECL is an affiliate member), SFP (Smoke Free Partnership, with whom ECL has a Memorandum of Understanding), EPHA (European Public Health Association, of which ECL is a member), HEAL (the Health and Environment Alliance, of which ECL is a member), ECPC (European Cancer Patient Organisation), SIOPE (the European Society for Paediatric Oncology), EONS (European Oncology Nursing Society), EPF (European Patients' Forum), ECCO (European CanCer Organization), ESMO (European Society for Medical Oncology), and EUROCARE (European Alcohol Policy Alliance).

Capacity building

Patient Support Working Group (PSWG)

The ECL secretariat coordinated and supported the ECL Patient Support Working Group (PSWG), chaired by the Dutch Cancer Society and co-chaired by the Portuguese League Against Cancer.

Access to Medicines Task Force (A2M TF)

The Secretariat co-ordinated and supported the ECL Access to Medicines Task Force, chaired by the Dutch Cancer Society until September 2019 and then by Stand up to Cancer Flanders from September 2019 onwards.

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

The Secretariat co-ordinated and supported the ECL Youth Ambassadors - a 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 within the European Code against Cancer. Through different events, campaigns and projects, Youth Ambassadors made creative and enterprising actions to promote cancer prevention.

Screening & Early Detection

The Secretariat convened member leagues to discuss the issue of integrating primary prevention with secondary prevention in the form of organised cancer screening programmes. 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 consider a common proposal for the development of the 3rd implementation report of the Council recommendation on cancer screening (2003).

European Fair Pricing Network (EFPN)

The Secretariat started initial conversations with cancer societies and the Netherlands Cancer Institute to create a network of organisations joining forces to push for fairer prices of cancer medicines while upkeeping the innovation pipeline and early access for patients to promising new medicines.

ECL Secretariat Activities

Advocacy

MEPs Against Cancer (MAC) Interest Group

ECL continued to provide the Secretariat for the MEPs Against Cancer (MAC) interest group at the European Parliament. ECL ensured to widely disseminate the MAC Elections Manifesto and to re-establish the group after the 2019 European elections.

EU initiatives, joint actions & projects

ECL held regular teleconferences with CHAFEA and DG SANTE and provided written contributions for briefings and speeches at the request of policy officers responsible for cancer.

ECL continued to be represented in the European Commission Initiative on Breast Cancer (ECIBC)'s Quality Assurance Quality Assurance Scheme development group by ECL's Senior Cancer Control Officer.

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).

ECL continued its engagement, as a subcontractor, in the EU Joint Action Innovative Action on Cancer Control (iPAAC) and the EU Joint Action on Vaccinations (EU-JAV).

ECL joined and took an active role in the transparency working group of the EU-funded stakeholder platform EURIPID (EUROpean Integrated Price Information Database project) - a collaboration between 27 European countries to exchange information on national prices of medicines in a standardised format.

ECL joined the EU Health Policy platform, actively contributing with relevant news and events.

Cancer Screening & Early Detection

The Secretariat hosted a breakfast policy round-table for EU Health Attachés from the permanent representations and missions to the EU under the auspices of the Permanent Representation of the Republic of Croatia to discuss developments made in cancer screening since the publication of the European Council Recommendation on Cancer Screening (2003) and consider revisiting this important and influential Recommendation.

ECL contributed to the European Parliament's motion for resolution on policy challenges and strategies against women's cancers and related comorbidities.

Cancer Research

ECL staff met with the European Commission's (DG RTD) staff during the European Research & Innovation Days 2019 to discuss cancer leagues' priorities for Horizon Europe's Mission on Cancer and present the position paper 'Uniting Europe Against Cancer: Challenge Accepted' - which was later discussed with Cancer Mission Board members Dr. Martine Piccart and Fiona Godfrey during ECL's annual meeting in November 2019.

Tobacco Control

ECL's Tobacco Control Advocacy Officer assisted in consolidating information and liaising with other organisations on various tobacco control issues, including illicit tobacco trade, the Tobacco Products Directive and the new edition of the 2019 Tobacco Control Scale report.





HIGHLIGHTS OF 2019

ECL Annual Meetings



The [ECL's 2019 annual meetings](#), which took place between 26-29 November, were hosted by the Foundation Cancer Luxembourg as part of the celebration of its 25th anniversary of service to their community and patients.

The 2019 ECL Conference put a spotlight on cancer prevention research, opportunities and challenges under the Horizon Europe's Mission on Cancer and the importance of cross-country collaboration. Cancer leagues also addressed the important topic of survivorship. As the population living with cancer grows and the majority of medical R&I focuses on product development and market approval, collaboration is of utmost importance for research into patient issues.

At the General Assembly, two new Board members were elected: Dr Lucienne Thommes (CEO of the Foundation Cancer Luxembourg) and Dr Darina Sedláková (Board Member of the League Against Cancer Slovakia).

All events were very successful. ECL is grateful to the Foundation Cancer Luxembourg for having hosted the events in Luxembourg City and for having taken very good care of the participants and organised plenty of well-received social events and networking opportunities.

ECL Patient Support Working Group

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 is chaired by Alrik Meesen (Dutch Cancer Society) and by Vice-Chair Monick Leal (Portuguese League Against Cancer) until Autumn 2021.

2019 Work Themes & Outputs

✓ **Improved volunteer services in patient services, support and care**

June 2019 - Published guide for cancer organisations on how to strategically develop and manage volunteer services for better patient support

✓ **Improved communication between cancer patients and healthcare professionals (HCPs)**

October 2019 - Published guide for patients on how they can get the most out of their medical consultations and improve communication with their teams of HCPs

2019 Meetings

- 6-7 May 2019, Helsinki, Finland
- 26-27 November 2019, Luxembourg City, Luxembourg





ECL Access To Medicines Task Force

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. In September 2019, Ward Rommel from Stand up to Cancer Flanders was elected the new Chair of the Task Force and took over from Eveline Scheres of the Dutch Cancer Society.

2019 Work Themes & Outputs

✓ Outputs & Advocacy

- Throughout 2019 - Presented the '[Let's Talk Access](#)' White Paper, launched in 2018, at national and EU events
- March 2019 - [Animation video](#) about the 'Let's Talk Access' White Paper
- June 2019 - [Position Paper](#) on the outcomes of WHO resolution on 'Improving the transparency of markets for medicines, vaccines and other health products'
- June 2019 - Responded to the Regulatory Science Strategy 2025 consultation of the European Medicines Agency (EMA)

- September 2019 - Responded to a WHO consultation on the definition of a fair price for medicines
- September 2019 - Organised a panel discussion at the 2019 ECCO Summit on how access to innovative cancer medicines relates to high-quality cancer care and well-functioning health systems

2019 Meetings

- 25 March 2019, Prague, Czech Republic
- 16-17 September 2019, Dublin, Ireland

New Chairmanship

Eveline Scheres from the Dutch Cancer Society who had chaired the Task Force since 2016, passed the baton to Ward Rommel from Stand Up to Cancer Flanders.





MEPs Against Cancer (MAC) Interest Group

The MEPs Against Cancer (MAC) Interest Group was founded in 2005 and remained the only dedicated group to cancer policy at the European Parliament. 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. ECL has been providing the Secretariat for MAC since 2010.

During 2019, the MAC elections manifesto, based on a survey among the MEPs to map their priorities in cancer control in the legislature 2019-2024, was widely adopted by nearly 100 MEP candidates and over 55 organisations and translated into 11 languages. After the elections, the group was successfully re-established, with almost 150 members subscribing to join the group in the legislature 2019-2024. MAC rebranded and elected new leadership. Loucas Fourlas (EPP, Cyprus) and Véronique Trillet-Lenoir (RE, France) were elected Chairs of MAC. Rory Palmer (S&D, UK) and Petra de Sutter (Greens/EFA, Belgium) became Vice-Chairs. The ECL secretariat further stepped up individual engagement with MEPs which resulted in increased requests for input to reports, parliamentary questions, and speeches.

2019 Meetings

- Internal Meeting for MEPs and Assistants, January 2019
- MAC Manifesto Press Conference at the European Parliament, January 2019
- MAC Manifesto Press Conference in Nicosia, Cyprus, March 2020

- MAC & ESMO stakeholders meeting - Shortages of Inexpensive, Essential Medicines: Calling for Tangible Political Commitments in the EU, April 2019 (MEPs José Inácio Faria (EPP, Portugal); MEP Lieve Wierinck (ALDE, Belgium); Cristian-Silviu Bușoi (EPP, Romania)
- Individual meetings and engagement with MEPs and their Assistants to present the view of cancer leagues and recruit them to become members of MAC for the legislature 2019-2024, June-December 2019
- Internal Meeting for the new cohort of MAC MEPs and Assistants, November 2019





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.

2019 Outputs & Achievements

✓ Tools

- October 2019 - development of an interactive map of the ECAC to be launched in 2020
- December 2019 - policy framework based on the ECAC outlining the supportive governmental actions needed for the implementation of the ECAC at the national and European levels

✓ Survey

- Throughout 2019 - collection of data and interviews to prepare the seventh Tobacco Control Scale which will be launched at the 8th European Conference on Tobacco or Health (ECToH) in 2020. The tobacco control scale quantifies the implementation of tobacco control policies at country level and is based on tobacco control policies described by the World Bank

✓ Letters & statements

- January 2019 - open letter to the Low Voltage Directive working party ahead of a meeting with DG GROW
- February - July 2019 - opinion articles on tobacco control issues (illicit trade, tobacco taxes, plain packaging and tobacco price levels)
- August 2019 - open letter to POLITICO regarding the sponsoring of the PRO Morning Health Care newsletter by British American Tobacco (BAT)
- September 2019 - cancer leagues' call for the creation of a dedicated, permanent working group on prevention and early detection under the umbrella of ECL to be formally launched in 2020

2019 Events

- Study visit at the Swiss Cancer League for the benefit of professionals working for cancer leagues specialising in the area of prevention, September 2019
- Workshop for cancer leagues focusing on the issue of partnerships required to implement the ECAC, May 2019

Cancer Prevention

Youth Ambassadors for the ECAC

The ECL Youth Ambassadors (YAs) 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 European Code Against Cancer (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 group increased substantially in 2019 growing to 66 members in 36 countries across the WHO European Region and carried out 205 actions throughout the year. Direct training for the ambassadors on effective methods for promoting ECAC is provided throughout the year through webinars and during their annual in-person meeting of the group. The 4th annual meeting ("summer school") was held in Ljubljana, hosted by the Association of Slovenian Cancer Societies and the Institute of Oncology Ljubljana. ECL also supported the group through direct grants to help with their activities and training needs, with 17 ambassadors (in 13 countries) receiving support to date in 2019.



✓ Actions

- Throughout 2019 - 16 teleconferences and internal meetings
- Throughout 2019 - 194 individual actions (including marathons and public 'fun runs', open lectures and seminars to the public)
- Throughout 2019 - 11 joint actions (including social media campaigns for World Cancer Day and European Week Against Cancer 2019)

2019 Events

- ECL & IARC webinar on environmental health and the ECAC, February 2019
- ECL & IARC webinar on cervical cancer prevention, April 2019
- ECL & SCPN webinar on diet, nutrition and cancer, June 2019
- ECL & ISPRO webinar on tobacco and cancer, November 2019
- Annual summer school in Slovenia, August 2019





Cancer Prevention

Cancer Screening

✓ Tools

- December 2019 - development of dedicated cancer screening webpages on ECL's website focused on information and activities relevant for cancer leagues

✓ Surveys

- February - March 2019 - cancer screening survey to collect data on the status of organised programmes in member leagues' countries and the role of the leagues in such programmes

✓ Articles, statements & press releases

- May 2019 - press release about lack of awareness as a major barrier to the early diagnosis following an Innovative Partnership for Action Against Cancer (iPAAC)'s conference
- July 2019 - opinion article regarding the available evidence on lung cancer screening
- October 2019 - experts consensus statement regarding the future monitoring and implementation of cancer screening activities in the EU

2019 Events

- Presented on the role of civil society in promoting organised screening at the Romanian National Forum of Gynaec-oncology, March 2019

- ECL first screening workshop focusing on the issue of integrating primary prevention with secondary prevention in the form of organised cancer screening programmes, May 2019
- First WP5 Conference of the iPAAC (Joint Action on Innovative Partnership for Action Against Cancer) Conference – 'Early diagnosis: five things you need to know', May 2019
- Presented on the role of European cancer leagues in promoting awareness of early detection at the Union for the Mediterranean, June 2019
- Kick-off meeting with experts including IARC and CPO Piemonte (WHO Collaborating Centre for Early Detection in Cancer) to provide strategic support and guidance to ECL's screening work, February 2019
- Meeting of the co-authors of the 2nd implementation report on cancer screening in the EU and invited experts to accelerate efforts to develop the 3rd implementation report on cancer screening in the EU, October 2019
- Breakfast policy roundtable for EU Health Attachés – 'latest developments in cancer screening programmes in Europe', October 2019
- Second WP5 iPAAC Conference – 'New openings of cancer screening in Europe', December 2019

EU-Funded Projects



ECL is an associated partner in the Horizon 2020 project MyPeBS (My Personal Breast Screening). MyPeBS is based on a large international clinical study that compares current screening with a new personalised screening approach based on estimating the individual risk of developing breast cancer in the coming years. This new strategy proposes to adapt the screening schedule to each woman's individual risk. ECL is task leader in the work package on communication focusing on communication to the public. In 2019, the Secretariat regularly communicated about the project's status and milestones through newsletters and update emails building on the stakeholder mapping and communication materials developed in 2018.



WASABY

ECL is an associated partner in the pilot preparatory action WASABY (Water and Soil contamination and Breast Cancer risk in Young Women), which focuses on the geographical analysis of population-based cancer incidence data in connection with environmental factors, using breast cancer and water/soil contamination as an example. ECL leads the work package on dissemination. In 2019, the ECL Secretariat created a working group of cancer leagues to discuss how to develop an online tool to raise awareness of cancer risk factors among adolescents and published a concept note for such a tool, which will be developed in 2020.

EU Joint Actions



EU-JAV (European Joint Action on Vaccination) - ECL is subcontracted by France's INSERM to help develop a strategy to communicate vaccination to young people, capitalising on experiences in previous Joint Actions. In 2019, with advice and dissemination efforts by ECL's Youth Ambassadors group, ECL organised a European school competition ahead of European Immunisation Week and gave prizes for the submissions which gained the most votes on social media. ECL also took part in teleconferences with the French Ministry for Solidarity and Health, leading the work package on sustainability (WP8).



iPAAC (Joint Action on Innovative Partnership for Action Against Cancer) - ECL is subcontracted by the Cancer Society of Finland in the work package on Prevention (WP5). In 2019, ECL participated in various teleconferences throughout the year, helped to conduct a survey on barriers to early detection, co-organised 2 conferences (one on early detection in Hungary in May, and another on screening in Finland in December) and chaired the working group session on prevention during the Governmental Board meeting in October 2019.



ECL MEMBERS

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

In 2019, ECL welcomed four new members, for a total of 30 members from 25 countries in the WHO European Region, covering 20 EU member states.

The Spanish Association Against Cancer, Cancer Research UK and O'Fonds Latvia joined ECL after the extraordinary general assembly in June 2019 and the Emanuele Cancer Research Foundation Malta became a member following the Annual General Assembly in November 2019 in Luxembourg.

ECL's members are non-profit cancer societies operating across the whole cancer continuum - 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.

Member leagues had a total of over 3,000 staff and 200,000 volunteers, representing over 500 million citizens in 2019. Member leagues raised more than €700 million for cancer research in 2018-2019.

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
The Faroe Islands' 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 League Against Tumours
O Fonds Latvia
Cancer Foundation Luxembourg
Emanuele Cancer Research Foundation Malta
Dutch Cancer Society
Polish Cancer League
Portuguese League Against Cancer
Romanian Cancer Society
League Against Cancer Slovakia
Association of Slovenian Cancer Societies
Spanish Association Against Cancer
Catalan Federation Against Cancer
Swiss Cancer League
Turkish Association for Cancer Research & Control
Cancer Focus Northern Ireland
Cancer Research UK

FINANCIAL REPORT



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

AUDITOR'S REPORT FOR THE FINANCIAL YEAR STARTED ON THE 1ST JANUARY 2019 AND ENDED ON THE 31 DECEMBER 2019 OF THE ASSOCIATION OF EUROPEAN CANCER LEAGUES (ECL) – RPR 0867.170.595

Objective and scope of the review

Upon the request of the Secretary General, we have reviewed the accompanying financial statements of ASSOCIATION OF EUROPEAN CANCER LEAGUES (ECL) AISBL as of December 31, 2019. The Board of Directors of ECL AISBL 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 € 828.036,77 as well as revenue in excess of expenses of € 31.518,69.

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.





FINANCIAL REPORT



Registered Auditors

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 31, 2019, 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.

The current revenues amount to € 630.400,16 and the expenses amount to € 598.881,47 and hence, the financial statement as at 31st December 2019 indicates revenue in excess of expenses of € 31.518,69.

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

The budget of 2020, as it stands today, almost cover the expenses of the association.

Conclusion

We have reviewed the accompanying financial statements of ASSOCIATION OF EUROPEAN CANCER LEAGUES (ECL) AISBL as at 31st of December 2019, prepared by its Board of Directors, indicating a balance sheet total of € 828.036,77 and revenue in excess of expenses of € 31.518,69.

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.

The annual account is prepared under the assumption of continuity. In the event that this assumption no longer applies, extra costs should be included in the annual accounts.

Brussels, February 25th, 2020

L&S Registered Auditors

represented by

Saskia LUTEIJN

Partner

FINANCIAL REPORT

European Cancer Leagues ASBL Chaussée de Louvain 479 1030 Brussels

BALANCE SHEET AS OF DECEMBER 31, 2019



ASSETS

FIXED ASSET

Website	8.396,70
Depreciation	-6.996,86
Furniture	8.202,79
Depreciation	-6.604,65
	2.997,98

AMOUNTS RECEIVABLE WITHIN ONE YEAR

Receivables	1.077,43
Other receivables	0,00
	1.077,43

CASH AT BANK AND IN HAND

BNP Paribas Fortis Bank	690.310,21
Business depo	12,60
Pretty cash	111,14
	690.433,95

DEFERRED CHARGES AND ACCRUED INCOME

Prepaid expenses	1.692,45
Accrued revenues	131.834,96
	133.527,41

TOTAL ASSETS

828.036,77



LIABILITIES

SOCIAL FUND OF THE ASSOCIATION

Social fund	37.110,00
	37.110,00

RESERVES

Social liability	212.000,00
	212.000,00

ACCUMULATED RESULT

Revenues in excess of expenses	194.825,64
	194.825,64

AMOUNTS PAYABLE WITHIN ONE YEAR

Suppliers and invoices to be received	41.754,98
Taxes to be paid	16.070,29
Salaries and social security to be paid	50.941,15
	108.766,42

ACCRUED CHARGES AND DEFERRED INCOME

Deferred income	275.334,71
	275.334,71

TOTAL LIABILITIES

828.036,77





FINANCIAL REPORT

European Cancer Leagues ASBL Chaussée de Louvain 479 1030 Brussels

P&L ACCOUNT AS OF DECEMBER 31,2019



OPERATING INCOME AND CHARGES

Turnover : Membership fees	179.728,60
Unrestricted grant / Donation	52.000,00
Grant EC	307.686,81
Other income	90.973,98
Total income	630.389,39
Services and other goods	-248.677,33
Remuneration and social security costs	-342.963,91
Depreciation and write-off on receivables	-5.547,23
Operating profit	33.200,92

FINANCIAL INCOME AND CHARGES

Financial income	10,77
Financial charges	-1.693,00
Current profit of the year	31.518,69

EXTRAORDINARY INCOMES AND CHARGES

Extraordinary incomes	0,00
Extraordinary charges	0,00
Withholding tax on financial income	0,00

REVENUES IN EXCESS OF EXPENSES **31.518,69**

FINANCIAL REPORT

ECL Income Sources 2019

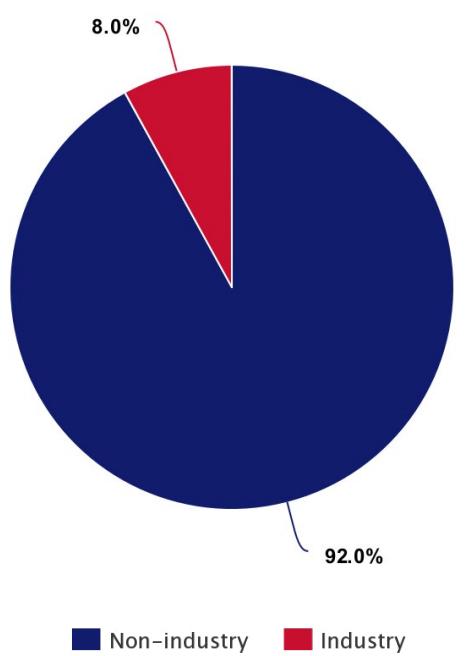
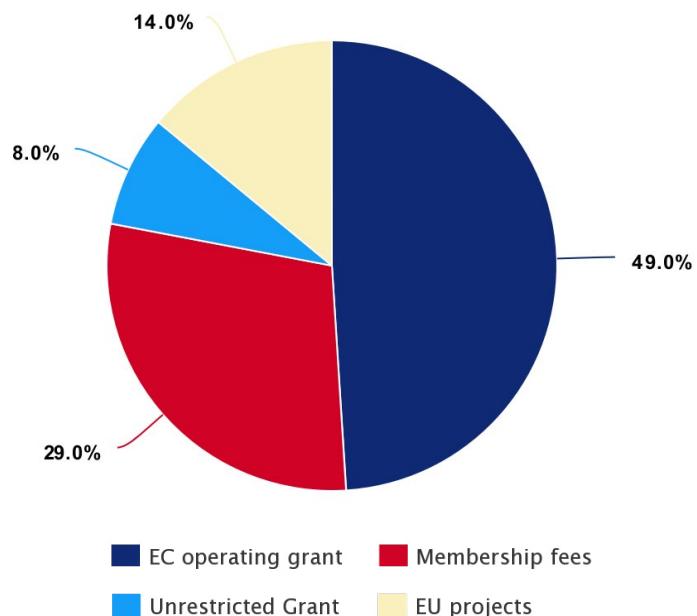
In 2019, ECL's total Operating Income was EUR 630,389.39.

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 2019 its contribution represented about 49% of ECL's total Operating Income.

In 2019, the total contribution from membership fees represented about 29% of the Operating Income. In addition to the operational budget, ECL is a partner in two EU-funded health research projects. An unrestricted educational grant from Garnier International represented the remainder of our income.

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.





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