



The newsletter of the Global Lung Cancer Coalition

Spring | Summer 2019

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WELCOME

In 2001, nine organizations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition. Today, the GLCC is comprised of 37 non-government patient organizations from around the world.

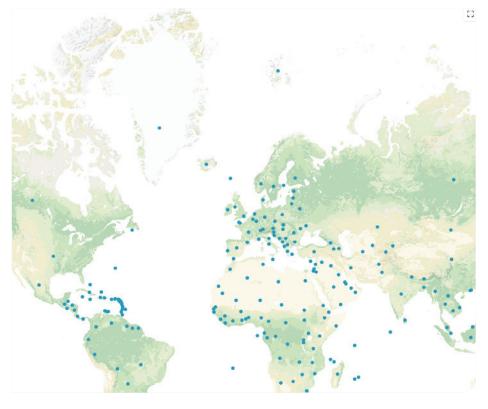
Our aim is to increase awareness of lung cancer issues, change perceptions of lung cancer, help people with lung cancer access the information and support they need, and push governments and legislative bodies to improve treatment and care.

Already, we have achieved a lot. But we also know that much more must to be done to improve the outcomes and lives of people affected by lung cancer – something we are determined to do.



To join us, please read our membership criteria, and download a membership application form at lungcancercoalition.org

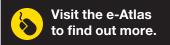
GLOBAL E-ATLAS DATA UPDATED



In late 2018, we updated our pioneering e-Atlas with new data from GLOBOCAN, the World Health Organization and national registries.

This means the global lung cancer community now has access to the most up-to-date information on global and national lung cancer incidence, mortality and survival by gender and age. The e-Atlas also details whether a country operates a cancer plan or has implemented the World Health Organization Framework Convention on Tobacco Control.

Users of the e-Atlas can use this data to compare countries, benchmark progress and campaign for change. To support this work, they can also create and export graphs, charts and infographics from the site, which could be used in presentations or meetings.



GOOGLE TRANSLATE

Please note that some articles in this newsletter have a Google Translate icon next to them. This is because the original news story for this article is in a language that's not English. To read the complete original story, please copy and paste it into **Google Translate** and select your appropriate language.

GLCC INTERVIEWS WITH LUNG CANCER EXPERTS

In the build up to the World Congress on Lung Cancer in Toronto in September 2018, we published interviews with eight lung cancer experts from across the world.

Our aim was to celebrate how treatments have improved over the years and the progress made in increasing awareness of the issues people with lung cancer face every day.

Among the experts who provided their views were two GLCC members: Dr Jesme Fox, Medical Director of the Roy Castle Lung Cancer Foundation, who focused on patient advocacy, and Vanessa Beattie, a specialist cancer nurse based in Liverpool, England, who focused on nursing.





Dr Jesme Fox

Vanessa Beattie



To read the interviews with the experts, please click here.

IRISH CANCER SOCIETY LAUNCHES 2019 CAMPAIGNS



The Irish Cancer Society launched its annual lung cancer awareness campaign in January 2019 and highlighted the substantial increase in women affected by the disease.

Following research by the National Cancer Registry Ireland (NCRI), the Society outlined that in Ireland the number of lung cancer cases in women could far outnumber men in the decades ahead. According to NCRI projections, annual cases of lung cancer could increase in males from 1,356 in 2015 to 2,633 in 2045 and in females from 1,130 in 2015 to 3,124 in 2045.



Please click here for more information.

In February 2019, the Irish Cancer Society also published its Lung Cancer Action Plan, which it hopes will help to save lives in Ireland by increasing the early detection of lung cancer.

Recommendations made in the plan include:

- A national communications campaign that encourages people to talk to their doctor if they notice changes such as a cough that doesn't go away, blood in phlegm or repeated chest infections.
- Targeted information and support for people who live in disadvantaged areas, where rates of lung cancer are highest.
- Advocating for the Irish government to deliver on its commitment to help over 500,000 people quit smoking by 2025.
- Increased investment in lung cancer research and clinical trials.

The Irish Cancer Society is also calling for more cancer nurse specialists in Ireland and increased psychological support for people with lung cancer, as the complex physical and emotional needs of these patients are often overlooked.

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Please click here for more information.

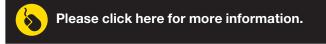
TACKLING A LACK OF EMPATHY

Lung Foundation Australia launched an eye-opening campaign at the beginning of 2019 to confront the severe lack of empathy for people living with lung cancer in Australia.

As part of the campaign, the Foundation promoted the following key messages to the public and media:

- Every hour an Australian watches a loved one die from lung cancer.
- Delayed diagnosis, a lack of research funding, and a reluctance to seek help are, in part, a result of more than a third (35%) of Aussies believing people with lung cancer are their "own worst enemy" who "have only themselves to blame".
- Half of lung cancer patients live with distress, anxiety and/or depression, on top of their diagnosis, and are four times more likely to take their life compared to people living with other cancers.

The campaign followed the Foundation's publication of *Making lung cancer a fair fight: A blueprint for reform* in October 2018. This groundbreaking report addresses the social, economic and mental health issues of Australians living with lung cancer.



CALENDAR OF HOPE



At the beginning of 2019, Lung Cancer Canada launched its Calendar of Hope

Featured throughout the calendar are 12 'Faces of Hope' and 12 months of practical tips on how to live well with lung cancer. The topics the tips cover include nutrition, clinical trials and exercise.

Please click here to find out more and download a PDF of the calendar.

BRAVO, AMIGO!



Peter Czanyo, the patient advocate who founded our Argentinian member organisation, Fundacion Pacientes de Cancer De Pulmon (FPCP), reached the summit of Mount Kilimanjaro in January 2019.

At the top of the Africa's highest mountain, which stands 5,895 metres above sea level, Peter proudly displayed a flag featuring the logos of FPCP and the Global Lung Cancer Coalition. He said his motivation for doing the climb was to show what is possible for people diagnosed with lung cancer, as it's 16 years since his diagnosis.

Peter also took centre stage in October 2018 when he appeared on the front cover of *The Lancet: Respiratory Magazine*, a prestigious UK-based medical journal. This was because Cecilia Raynoso, a documentary photographer based in Bueno Aries, Argentina, met Peter at a local running club and was so inspired by his story that she wrote an article about him.



Please click here to read more about Peter's climb up Mount Kilimanjaro.



Please click here to read the full article featured in *The Lancet: Respiratory Magazine.*



LUNG CANCER AWARENESS MONTH SUCCESS

Last November, GLCC members across the world held events for Lung Cancer Awareness Month to spread the word about the biggest cancer killer. Highlights included:



Australia

Lung Foundation Australia held a Parliamentary Friends of Lung Health event that was attended by politicians and key opinion leaders to mark the launch of Lung Cancer Awareness Month.



Brazil

Oncoguia Institute organized the country's second annual conference on lung cancer.



Europe

WALCE held makeover workshops to help women with cancer cope better with the side effects caused by the illness and treatment.



Italy

ALCASE Italia held its Illumina Novembre (Enlighten November) event, which involves communities throughout Italy dressing buildings, landmarks and their homes with white lights, balloons and ribbons, as well as people wearing white ribbons and clothing.



Mexico

Respirando Con Valor worked with former NFL star Chris Draft to promote lung cancer awareness. Chris is leading a major campaign to change the face of lung cancer, after his wife, Keasha, died of lung cancer in 2011.



Netherlands

Longkanker Nederland organized a national meeting for people with lung cancer and their loved ones, which involved presentations, workshops and an information market.



USA

Prevent Cancer Foundation brought together experts and leaders in science, policy and practice at a workshop for the advancement of quantitative CT imaging biomarkers to manage early thoracic disease.

Lung Cancer Research Foundation held its signature gala, the Sixteenth Strolling Supper, at Gotham Hall in New York City. The event, which raised over \$1.3 million, featured a special performance by Sutton Foster, a Tony Award winner and star of *Younger*.

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NEW EXECUTIVE DIRECTOR FOR THE LUNG CANCER RESEARCH FOUNDATION

The Lung Cancer Research Foundation in the US announced Dennis P Chillemi as its new executive director in November 2018.



In his role, Dennis will focus on growing the impact of the Lung Cancer

Research Foundation (LCRF) on a national level, drive awareness and raise much needed funds to support cutting-edge research in lung cancer.



Please click here for more information about Dennis P Chillemi's appointment.

STIGMA REPORT LAUNCHED IN CANADA



A survey conducted by the Canadian Lung Association has revealed that Canadians with lung cancer report social isolation, self-blame and delayed treatment because of stigma surrounding their disease.

For example:

- 55% of respondents living with lung cancer reported social isolation due to stigma.
- 45% of respondents living with lung cancer reported they had put off doctor visits due to self-blame.
- 42% of respondents living with lung cancer felt less deserving of help.

The survey, which involved 1,500 people and was published in September 2018, also focused on people with asthma, COPD and other chronic lung diseases, who reported similar experiences to those living with lung cancer.

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To read the Canadian Lung Association's full *Stigma Report 2018*, please click here.





NEW COALITION FORMED IN LATIN AMERICA



With the aim of promoting greater access to quality treatments, early diagnosis and prevention measures, the Latin American Union Against Lung Cancer (ULACPUL) was officially established in September 2018.

Included among the founders of the new organization are Peru's Esperantra and Mexico's Respirando Con Valor, who are also members of the GLCC.

At the launch of ULACPUL, Patricia Mondragón, President of Respirando Con Valor, said the problems faced by lung cancer patients across Latin America have many similarities, despite different health systems:

"Lung cancer is a stigmatized condition because it is believed that those affected earn it by smoking, a situation that permeates not only in the collective of people but also in the care sectors. Our fight aims to ensure that the health sector, both at a private and public level, offers access to innovative and high-end medicines."



NORWEGIAN MEMBER CELEBRATES 10TH BIRTHDAY

On 9 November 2018, Norway's Lungekreft Foreningen celebrated 10 years since its foundation.

During the past decade, the organization has worked hard to increase the Norwegian public's knowledge about lung cancer, support research projects, and provide information and help to those living with the illness and their families.

One of the ways it aims to build on this work in the future is through its new website, which was officially launched on the day of its 10th birthday. In addition, Lungekreft Foreningen has set its sights on growing its membership to 1,000 in 2019, helping it reach out to even more people in Norway.



Please click here for more information. Google Translate

SCREAMING TOGETHER AGAINST LUNG CANCER



During Lung Cancer Awareness Month 2018, Portugal's Pulmonale and pharmaceutical company Bristol Myers Squibb, with support from Infraestruturas de Portugal, launched the 'Scream at the Top of Your Lungs' campaign.

Its goal is to get the Portuguese public to scream against lung cancer, which is the second leading cause of cancer death in Portugal, with 4,200 new cases every year. This involved 54 interactive digital advertising screens being placed in Lisbon, Porto, Viseu and Figueira da Foz, which gave people the opportunity to take a photo and show their support for the campaign.



Please click here for more information. Google Translate

ROY CASTLE LUNG CANCER FOUNDATION LAUNCHES #LIKEME



The UK's Roy Castle Lung Cancer Foundation launched its #LikeMe campaign in April 2019. which aims to highlight that lung cancer can affect anyone.

Initially, the campaign is focusing on reaching two core groups: younger women and family doctors. This is because even though lung cancer is a leading cause of cancer deaths for women aged under 50, many women are unaware that they could be at risk, even if they've never smoked. While family doctors may believe that an apparently healthy younger woman with relatively minor or vague symptoms could, in fact, have lung cancer.

Fronting the campaign are 10 women aged 30 to 50 who have been diagnosed with lung cancer. They feature on #LikeMe posters and leaflets and in videos in which they talk about their diagnosis and hopes for the future. In addition, people can also order a campaign pack and download materials to help spread the word that anyone can get lung cancer, regardless of age, gender or lifestyle.



Please click here for more information.

RECOGNIZING LUNG CANCER SYMPTOMS IN YOUNG SWEDISH WOMEN

Representatives from Lungcancerföreningen, our member organization in Sweden, have called for better recognition of lung cancer among younger Swedish women who have never smoked.

Mia Rajalin and Yann Fränckel, who are both living with lung cancer, highlighted in an article for the Swedish newspaper Svenska Dagbladet that when this patient group presents to primary care, staff often fail to recognize symptoms as signs of lung cancer, leading to devastating consequences.

Citing their own experiences, one of the writers revealed that they had visited their health center and emergency clinics with serious symptoms 16 times before a lung X-ray was taken. While the other said she was only sent for an X-ray after 13 visits to primary care. Both were found to have lung cancer after these regular chest X-rays; and in both cases, the lung cancer is incurable.



Please click here for more information.

LUNG CANCER TALKING CARDS



Longkanker Nederlands, along with the Dutch Federation of Cancer Patient Organizations (NFK) and Pharos (Dutch Centre of Expertise on Health Disparities), have developed four talking cards for professionals to help them communicate effectively with people with lung cancer who have low literacy levels.

In addition, the three organizations also worked together to develop 'Effective Communication' training for pulmonary oncology nurses and nursing specialists. During the course, participants learn how to recognize low literacy and low health skills in people with lung cancer.



Please click here for more information.



LUNG CANCER MEDIA ROUND-UP

HIGHLIGHTS FROM 2018 IASLC WORLD CONFERENCE ON LUNG CANCER

Check out all the news from the 2018 conference in Toronto, Canada. This includes the long-awaited results from the NELSON study, which reported a 26% reduction in lung cancer deaths when high-risk patients had a CT scan.



Please click here for more information.

ISRAEL RESEARCHERS USE BLOOD TEST TO MATCH TREATMENT TO LUNG CANCER

Researchers at Soroka Hospital in southern Israel have developed a method that uses the Guardant360 test to precisely match treatment to lung cancer patients. The Guardant360 is a non-invasive liquid biopsy test that detects DNA segments in the patient's blood which originated from a tumor or its metastasis.



Please click here for more information.

ARTIFICIAL INTELLIGENCE CAN DETERMINE LUNG CANCER TYPE

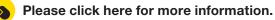
A study led by researchers at New York University in the US has shown that a new computer program can analyze images of patients' lung tumors, specify cancer types, and even identify altered genes driving abnormal cell growth.



Please click here for more information.

NHS ENGLAND ANNOUNCES LUNG **CANCER SCANNING TRUCKS PROJECT**

A six-minute video assessing NHS England's new £70-million lung cancer project, which will involve lung cancer screening trucks operating from supermarkets and offering people on the spot chest scans.



DROP IN DISCUSSIONS ABOUT LUNG CANCER SCREENING

In the US, low rates of physician-patient discussions about lung cancer screening have declined further since 2012, according to results published in Cancer Epidemiology, Biomarkers & Prevention, a journal of the American Association for Cancer Research.

In 2017, the prevalence of patient-physician discussions about lung cancer screening was only 4.3% in the general population and 8.7% among current smokers, down from 6.7% and 12% respectively in 2012.

Please click here for more information.

LUNG CANCER ADVANCES: A YEAR LIKE NO OTHER

A 16-minute video in which US cancer experts Dr Mark Kris, Dr Pasi A Jänne and Dr Christian Rolfo discuss recent clinical advances in the treatment of lung cancer.

Important: you will need to register for free at medscape.com to view this video.



Please click here for more information.

IT'S NEVER TOO LATE TO QUIT SMOKING BEFORE LUNG SURGERY

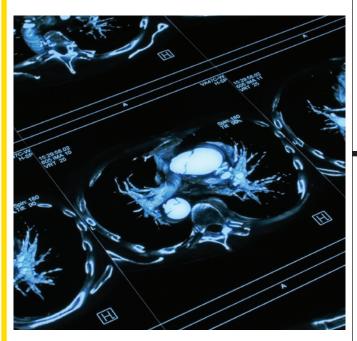
A study conducted by researchers from the Juntendo University School of Medicine in Tokyo, Japan, has highlighted that quitting smoking even just a few months before lung cancer surgery can reduce risks of complications.



Please click here for more information.

LUNG CANCER MEDIA ROUND-UP

UK RESEARCHERS USE GENETIC PROFILING TO PREDICT LUNG CANCER



Researchers at University College London in the UK have used molecular profiling to identify differences between lesions in the airway that lead to lung cancer and those that are harmless. These findings could improve the early detection and treatment of people with lung cancer.

Please click here for more information.

CANCER STATISTICS REPORT HIGHLIGHTS YOUNG WOMEN AND LUNG CANCER PUZZLE

The new 2019 cancer statistics report from the American Cancer Society has revealed some interesting findings regarding lung cancer incidence in men and women in the US. Currently, lung cancer incidence continues to decline twice as fast in men as in women, reflecting historical differences in tobacco uptake and cessations, as well as upturns in female smoking prevalence in some birth cohorts. However, smoking patterns do not appear to explain the higher lung cancer incidence rates recently reported in young women compared with men born around the 1960s.

Please click here to read the full report.

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NEW STANDARD OF CARE IN SMALL CELL LUNG CANCER?

Results from the IMpower133 study in the US have shown that the overall survival of patients with extensivestage small cell lung cancer improved when concurrent immunotherapy was added to standard chemotherapy in the first-line setting.

Please click here for more information.

£2.4 MILLION RESEARCH PROJECT IN THE UK TO MAP OUT LUNG CANCER IMMUNOLOGY



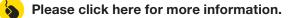
A 'rule book' to guide precision combination immunotherapies and speed up the development of new lung cancer treatments will be created as part of a collaboration between Cancer Research UK, the Francis Crick Institute and Bristol-Myers Squibb.



Please click here for more information.

BEAGLE DOGS SNIFF OUT LUNG CANCER IN BLOOD SAMPLES

New preliminary research conducted in a Florida-based pharmaceutical lab has suggested that dogs can sniff out lung cancer in samples of human blood. Using their super-sensitive noses in experiments, three of four beagles correctly identified samples of blood with lung cancer 96.7% of the time.



LUNG CANCER MEDIA ROUND-UP

SMOKING UNFILTERED CIGARETTES ALMOST DOUBLES RISK OF DYING **FROM LUNG CANCER**

Findings from a study led by researchers at the Medical University of South Carolina have revealed that people who smoke unfiltered cigarettes are 40% more likely to develop lung cancer and nearly twice as likely to die from it than those who smoke filtered cigarettes.

The study also found that people who smoke unfiltered cigarettes are more dependent on nicotine and 30% more likely to die of any cause than filtered cigarette smokers.

But the chances of developing or dying from lung cancer were no different between smokers of regular filtered cigarettes and those who smoke "light" or "ultralight" ones.



Please click here for more information.

LESS INVASIVE SURGERY FOR FASTER RECOVERY?

The results of a large clinical study may pave the way for the widespread use of less invasive surgery to treat people with lung cancer who require a lobe removing from one of their lungs.

At the annual meeting of the American Association for Thoracic Surgery, researchers from the University of Montreal Hospital Research Centre presented findings that showed thoracoscopic lobectomy - video-assisted thoracoscopic surgery (VATS) - combined with pulmonary artery sealing using an ultrasonic energy device reduces the risk of post-operative bleeding, complications and pain.

Currently, only 15% of lobectomies around the world are performed by VATS.

Please click here for more information.

NEWS ON LUNG CANCER GUIDELINES

DOWNLOADS OF NCCN GUIDELINES TOP 10 MILLION IN 2018

The National Comprehensive Cancer Network announces its NCCN Clinical Practice Guidelines in Oncology were downloaded more than 10 million times in 2018. This included more than 400,000 downloads of its non-small cell lung cancer guidelines, which underwent six separate updates during the past year. The recommendations made in the free guidelines are determined by multidisciplinary panels of cancer type-specific experts from the 28 leading academic cancer centers.



Please click here for more information.

NON-SMALL CELL LUNG CANCER **CLINICAL PRACTICE GUIDELINES (SPAIN)**

The Spanish Society of Medical Oncology released new guidelines on non-small cell lung cancer in November 2018.

Please click here for more information.

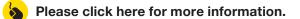
METASTATIC NON-SMALL CELL LUNG CANCER CLINICAL PRACTICE **GUIDELINES (EUROPE)**

The European Society for Medical Oncology released new guidelines on metastatic non-small cell lung cancer in October 2018.

Please click here for more information.

UK'S NICE PUBLISHES NEW LUNG CANCER GUIDELINES

The UK's National Institute for Health and Care Excellence (NICE) has updated its guidelines for diagnosing and managing non-small cell and small cell lung cancer. The organization has also created new systemic algorithms for the treatment of advanced squamous NSCLC and advanced non-squamous NSCLC.



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HOW TO... Start a podcast

Following requests from GLCC members, *Unity* will now include a regular 'How to...' feature to help organizations make the most of social media and boost their marketing. In the first of the series, we provide seven easy-to-follow steps on how to record, edit and publish a podcast. Something you may want to do to promote your organization's work, give your supporters a voice, or broadcast interviews with figures from your organization or the world of lung cancer.





Your audience

Consider who you want to connect with and what will engage them with your podcast.

Content

Decide what sort of content you want to provide. Do you want to inspire people to take action, provide educational information or achieve some other goal?

Agenda and guests

Develop a regular running order for your podcast, such as an intro, latest news, interview with a guest, outro. Also consider who you'd like to feature on your podcast. Develop questions or a script for each guest.

Commitment

Consider how much time it will take to produce each podcast and whether you can consistently commit to creating new content.



Microphone

Laptop and headset microphones won't do. For a podcast, you'll need to choose between a USB or analog microphone.

USB microphones are cheaper and can be simply plugged into your computer's USB port. But they do have limitations.

An analog microphone will deliver better sound, and is a good choice if your podcast will regularly feature multiple speakers.

Audio interface

This connects microphones to a computer, which means you won't need it if you're going to just use one USB microphone. A second hand or lower end interface (under \$100) should be fine when starting out on your podcast journey.

Headphones

When recording a podcast, it's beneficial to wear over-ear headphones, as they will help you hear things more clearly, including people you're interviewing and background noise you need to cancel out. Again, you don't need to spend too much (\$100–200) to get some good quality headphones.

Editing software

A good podcast needs editing. The most popular free audio editor for a PC or Mac is Audacity **(audacityteam.org)**, which should feel accessible and meet all your needs. Alternatively, if you have a Mac, you could use GarageBand to edit your podcast, which should be pre-installed on your computer.

3. Select a name, design and theme music

Podcast's name

Take time to think of a name that's ideally descriptive and will sound appealing to your audience.

Cover art

In a podcast directory, people will view the title of your podcast and cover art (think album cover). This could simply be your organization's logo or something a bit more creative that gives people a flavor of what your podcast is about.

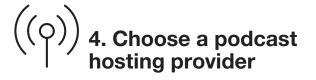


Podcast description

If someone clicks on the name/cover art of your podcast in a directory, they will then expect to see a description of what your podcast is about. Try to write a description that sounds interesting and features keywords you may want people to search for, such as "lung cancer", "living with lung cancer", etc.

Theme music

This may sound like an extravagance, but intro and outro music can really help your podcast sound professional. And the good news is you can search for and then edit free music at Free Music Archive **(freemusicarchive.org)**, or pay a small amount for more professional music at Audio Jungle **(audiojungle.net)**.



It's important you pick a good quality host, so listeners of your podcast don't have any trouble downloading or streaming it. Therefore, you may want to carry out some research on the best podcast hosting providers in your country; or alternatively, select one of the world's leading hosts, which include Soundcloud (soundcloud.com/pro), Podbean (podbean.com), Podomatic (podomatic.com) and Libsyn (libsyn.com).

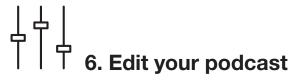


Plug in your microphone and launch the editing software we talked about in Step 1. Audacity and GarageBand both have recording options. Or if you already have editing software, or have chosen a different program, it's highly likely that this will be able to record too.

When recording, the main issue you'll need to think about is whether it's going to be a podcast that involves one person, multiple people in the studio or multiple people in different locations.

For one person (solo podcast), it's just a case of selecting your microphone in your recording software and pressing 'record'.

For multiple people in the same room, you'll need to have a microphone for each person, an audio interface and the right software setup, as Audacity only supports one input. For information on how to create this setup for Windows, please **click here**, and for Mac computers, please **click here**. For multiple people in different locations, the best options are to use Skype and either Pamela (pamela.biz) or MP3 Skype Recorder **(voipcallrecording.com)** to record conversations. Both have free and paid versions.



The first thing you'll need to do is import all your audio clips into your editing software and give them names that make it easy for you to identify their content. It's then a case of editing your clips (intro, interviews, outro, etc) together to create the podcast you want to publish. To help you do this, your software should feature a tutorial. For example, Audacity provides an **online tutorial for editing an audio file**.

Once you've completed the edit of your podcast, you'll then need to export it as an MP3 file, with a bitrate of at least 128kbps and a sample rate of 44.1 kHz (usually default setting). In addition, you'll also need to tag your file with labels, including track, title, artist, album, year, comment (ie description). These can be important in helping people find your podcast.



7. Publish and promote your podcast

To publish your podcast, simply upload it to your hosting provider. Then list it on the following leading directories and any other ones you think are relevant. Typically, this involves adding your RSS feed.

- iTunes
- Google Play
- Stitcher
- Blubrry
- Pocketcasts

After listing your podcast, it will then be worth promoting it to your organization's email subscribers, in your newsletter, and on your website. In addition, you may also want to publish your podcast on your website. If your website is a WordPress site, you can easily do this by using **Blubrry's PowerPress plug-in**. Alternatively, speak to your IT team or website host about how best to upload your podcast to your site.

> For further information on all the above, please take a look at the following blog: How to start a podcast in 2019: A step-bystep guide.





In 2019, the GLCC acknowledges the support of its sustaining partners: **AstraZeneca, Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Eli Lilly, Merck, Novartis, Pfizer, Roche, Takeda.**

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