RARE CANCERS
EUROPE
Joining forces for action

„SPEAK UP FOR RARE CANCERS!“

RARE CANCER
PATIENT TOOL KIT
Introduction

This rare cancer patient tool kit has been designed to help rare cancer patient groups speak up about what their special needs are and to raise awareness about rare cancers. It has been written by Rare Cancers Europe representatives from patient groups, doctors, European Affairs specialists and a health journalist, who all have first-hand experience of the challenges faced by those diagnosed with a rare cancer.

- **Who this tool kit is for**
  - Rare cancer patient groups

- **How/when to use**
  - When preparing to raise awareness of patients’ needs
  - When speaking to authorities or the public, in order to make rare cancer patients’ lives better
  - When areas for change have been identified
Why speak up?

Most newly diagnosed cancer patients (and their families) hope that their doctors will have the remedy for their illness.

Rare cancer patients often experience the double shock of:
- Rare cancer diagnosis
- Lack of effective treatments / knowledge about their particular cancer

The “patient voice” and “perspective” are vital to raise awareness amongst the general public and those who determine health services. If we do not make our governments and health providers aware of our needs they will quite naturally assume that we are OK and have no need for attention.

“Lobbying” on behalf of rare cancer patients may not always be the first priority for patient groups. Often, patient groups start as individuals or small groups of patients trying to help one another with information and advice about their personal experiences, lending an ear and sharing information about who and where the most knowledgeable doctors might be. As patient groups develop, it eventually becomes obvious that to improve services, legislation is required to mandate what should be happening in the provision of care for rare cancer patients. This is where “lobbying” becomes important.

Why lobby?

Patients have a unique perspective on the problems they face. Politicians and Senior Health Officials are busy and have enormous and varied roles to fulfil. This means that the detail and reality of patient experience is often lost to them.

Hearing the constructive views of patients who are experiencing “the system” first hand can touch the emotions and influence policy makers. “What if this was happening to them or one of their loved ones?”

Speaking out and drawing attention to our rare cancer patient needs puts us “on the agenda”.

What you need to communicate and to whom

Rare cancer patients and their families need and want improvements in diagnosis and treatments. Society, health authorities and legislators need to be made aware of these urgent needs and encouraged to take action.

To make sure that you have the desired impact, you need to equip yourself and your team/supporters with a list of specific needs:
- Identify your needs
- Prepare some basic data/information about your rare cancer (a poster is useful as it summarises everything that you want/need in a simple format)
- What are you aiming to achieve?
- Prepare simple documents to bring your needs to life, so that you can send or leave them behind after a meeting
- If possible create a website, Facebook page and Twitter account so that you have a social media presence that your supporters and those you lobby can refer to
- Identify your audience (health authorities, local authorities, medical society, industry)
- Clarify your key messages
- Evaluate your resources (volunteers, budget, time required, contacts)
- Go for it!
When to speak

How to lobby

Taking the leap from being a patient or someone who supports/cares for a patient to one who engages with authorities can seem a daunting task and will not happen overnight.

It is vital to network and understand who else has similar needs and interests to your own. Rare Cancers Europe is a hub for many rare cancer groups and can offer advice, guidance and introductions to groups that may help your cause.

There may already be groups in your country that are experienced in lobbying and can help to introduce and guide you.

For example, in the UK groups such as Cancer 52, SCHA (the Specialised Healthcare Alliance) and the Genetics Alliance/Rare Diseases UK have well-developed networks and contacts. They make a point of hosting lobbying sessions that can be used as a platform to promote your cause. Engaging with groups such as these accelerates access to the decision and policy makers to make your case in your country.

Engage with your local politician(s) – they can help raise awareness of the needs of your patient group and open access to meetings with relevant senior health decision makers.

Engage with Members of the European Parliament (MEP), especially those that have an interest in health issues.

What to say

Topics you should be prepared to speak about:

- Inequalities in Rare Cancer
  - Diagnosis
  - Referral
  - Research – where is it happening?
- Patient consent (storage and use of tissues in biobanks)
- Patient participation in clinical trials
- Patient-reported outcomes
- Need for Centres of Excellence in Europe for rare cancers
- Need for European Reference Networks to be set up for rare cancers

For suggestions on what to say, read the RCE recommendations: http://www.rarecancerseurope.org/Rare_Cancers_recommendations_2010.pdf
Key messages

Inequalities in Rare Cancers
- Five-year relative survival rates are worse for rare cancers in adults (47%) than for common cancers (65%)
- Survival rates differ significantly across Europe (gaps between Northern/Western Europe and Eastern Europe)
- Patient access to new cancer drugs is not equitable across Europe

Research
- Rare Cancer treatment not as attractive for the pharmaceutical industry (return on investment lower than for other cancers)
- Randomised clinical trials considered not possible for rare cancers due to small numbers
- Poor acceptance of adaptive designs and lower level evidence by regulators
- Randomised clinical trials are feasible (except for ultra-rare cancers)
- Need for large international collaboration
- Need for incentives (funding)
- Methodology concerns/Study design
- Enrolment issues
- Production issues (small quantities in each country)
- Reimbursement issues
- Paediatric specificity (long-term safety issues)
- Post Marketing Authorization issues

Patient participation in clinical trials
- Cross-border participation in clinical trials
- Patient involvement in the design of clinical trials
- Better information of ongoing clinical trials and their results

Reimbursement
- Of second opinion
- Of innovative treatments (criteria should be different than for other cancers)
- Of “off label” use of drugs

Diagnosis
- Rare cancers are often misdiagnosed, leading to late or inadequate treatment
- Rare cancer diagnostics require expert opinion
- Need for referral (second, reimbursed, opinion)
- Experts may not be available in the country where the patient lives
- Need for cross-border referral
- Experts and reference centres are poorly known to patients and doctors
- Patient referral is sub-optimal (long delays)
- Biological material may not be readily available
- Quality of pathological material not always adequate or quantity insufficient
- Need for a system in place that would swiftly direct rare cancer patients to an expert centre together with appropriate data and good quality material

Treatment
- Few therapeutic options
- Treatment based on low level of evidence
- Frequent “off label” use of drugs
- Of second opinion
- Of innovative treatments (criteria should be different than for other cancers)
- Of “off label” use of drugs
Key messages

Patient consent

» Informed consent needs to be more “patient friendly” (easy to understand wording)
» Need for enduring (withdrawable) patient consent

Centres of excellence

» Need for Centres of Excellence where patients can be referred for second opinion and treatment

European Reference Networks

» Need to implement the ‘EU Directive on Patient’s Rights to Cross-border Healthcare’ (Directive 2011/24/EU) in order to allow prompt referral of rare cancer patients for timely and accurate diagnosis
» Provisions for transfer of tissues

How to say it?

Communication is key to creating awareness about your messages

» Prepare clear information about your rare cancer and what you are aiming to achieve
» Prepare a campaign/call to action/event/press conference (establishing goals, priorities, timelines, resources needed, potential partners, funding, outcomes)
» Join with others to create awareness (need to establish a list of local/national/international/umbrella patient associations/healthcare professional societies dealing with rare cancers)
» Hosting events and making sure everyone knows about them
» Communicating with the public through media

Tips for working with media

The media helps to relay important messages about rare cancers to large audiences. Here are some tips to help you reach out:

» Determine your target audience: Are you trying to reach your local community, other patients, local authorities, healthcare authorities or European authorities? Find out which media outlets and specific reporters reach that audience and would welcome your story.

» Prepare a media list and keep it up to date: Call or Google newspapers, magazines, radio stations, local TV, websites, bloggers and vloggers and ask/find contacts of reporters for healthcare/community issues. If you have funds, there are service providers that can help build media lists and disseminate information (AlphaGalileo, EurekAlert, Cision Point, Vocus PR).

» Send an email to contacts when you have news, attach your media alert or press release and ask them to run or comment on it in their publication. Offer to provide more background, spokespersons, testimonials, patient and care giver stories and facts and figures that will make the news more relevant to their readers.

» You can use free services such as http://mailchimp.com for sending out group emails and keeping track of who opened them.
How to say it?

» Make a list of your 10 main local contacts and keep up the relationship: follow them on Twitter, comment on their articles online, retweet their relevant tweets, invite them to your events. When you have a special event, after sending a media alert, you can make a follow-up call to them to promote your event, campaign, interview. Include a fact sheet about rare cancers/your specific rare cancer. Follow-up calls, where you explain why this campaign/interview/event is important, can make all the difference!

» Include contacts of other stakeholders in your list, such as local hospitals, sister patient associations, local medical societies, and relevant industry partners if any, engage with them on Twitter, LinkedIn and Facebook and keep them in your mailing list too.

» Organise your list so you can view key information at-a-glance. Organise your list by the reporter or editor’s name, media organisation, their specific area of interest, phone number, email address, and fax number.

» If your association is new, introduce yourself with an email: Tell your contacts the aims of your association, your availability, explain your role and the type of information you can provide, and give them your contact information. You can also attach a fact sheet about rare cancers/your specific rare cancer. Keep it short. People tend to ignore long emails or only read the first paragraph.

» Facts and personal stories make news: Use key messages and statistics about rare cancers in your country/area to grab media’s attentions. For example:
  - Capitalise on local events. Watch for national or international events related to cancer/health/research/legislation and use them to create a story with a local angle.
  - Find patients who have overcome obstacles to advance the cause of rare cancers and ask them to speak about their experience in an interview.
  - Host a special rare cancer event and find key spokespersons and sponsors to help promote it in local media.

» If a reporter or editor has specific questions about rare cancers that you do not feel comfortable answering, direct them to speak with a local healthcare professional (identify rare cancers spokespersons in your area). Be honest about what you can and cannot answer.

» Consider formal media training (if your organisation has sufficient funding) on how to answer difficult questions that might be put to you in interviews.

Sample media email

Dear XXX

Rare cancers affect over 4 million people in the European Union. Most of them lack treatment. Despite the rarity of each of the 186 rare cancers, they represent in total about 22% of all cancer cases, including all cancers in children, diagnosed in the EU27 each year. In (name of your country, region town), 30 000 rare cancers are diagnosed annually (if you have local figures, use them here). These numbers make it essential for our community to help patients find adequate and timely treatment.

Here in (your country, town…) the (name of your association) is holding an event on (date) at (place) with (…) to create awareness about the hurdles that patients face when diagnosed with a rare cancer. We (name of your association) will (meet authorities, hold a press conference, media brief, etc) to ask for the urgent creation of a Centre of Excellence dedicated to rare cancers in (region/town/county).

Please help us get the word out to our community about the importance of this campaign. I’d be happy to give you more information about what (name of your organisation) is doing to help promote this campaign in (name of your town/country/region) and more facts and figures about rare cancers (or the specific cause you are defending). We would be happy to see you on (date and time of your event, meeting). For more information, visit our website (link) or contact me at (your phone, email). Thanks (your name).

Our association is part of Rare Cancers Europe (RCE) a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda and to implementing 39 political and stakeholder recommendations.

Contact us on: (email, phone numbers, Twitter and Facebook links)
Sample letter

The Honourable XXXX
House of Commons
SW XXXX London

Ms Julia Smith
Rare Cancers UK
XXX Old Church Road
WWW WWW Cambridge

Date

On behalf of rare cancer patients in the UK
Dear (Minister)

As a constituent and rare cancers patient advocate, I am writing to urge you to ensure that the current legislation reform the government is undertaking provides rare cancer patients proper access to rare cancers Centres of Excellence and European Reference Networks, in accordance with the EU Directive XXXX.

Rare Cancers XXX recently released its 2014 Rare Cancers Priority Agenda (available at: http://www.XXX.advocacy/resources/). This document highlights the changes we must make to improve diagnosis and treatment of Rare Cancers in (your country), based on current evidence and on our longstanding advocacy efforts.

Specifically, Rare Cancers (your country) is recommending that new health legislation works towards removing the red tape which makes access to new treatments difficult for rare cancer patients. We urge you to include the following provisions:

• Standardise second opinions, scans & mutational analysis
• Reimburse second opinions and diagnostic tools
• Improve access to existing treatments including drug approval for small groups
• Reimbursement for “off label” use of existing and licensed drugs in Europe
• Educate doctors and pathologists to recognise rare cancers earlier (primary care / GPs)
• An infrastructure supporting translational research / cross-border cooperation:
  - Tumour banks & easy tissue transfer for research
  - Clinical trials on an international scale to maximise patient numbers
  - Harmonised European patient data registries
  - Access to patient data – data protection regulation should facilitate access for health research

We urge you to work to ensure that these key provisions are considered as Parliament moves forward with efforts to reform our nation's health system. Thank you for your attention to my request and I look forward to hearing your position on this critical issue.

Yours sincerely,

(Name)

(Postal and email address)

(Telephone number)

This letter has been copied to:
• The Hon XXX XXXX, Minister of Health
• Dr XXX XXXX, Director for XXXX
• Dr XXX XXXX, Undersecretary for XXXX
• Etc.

Presentation skills

1. Cover letter for authorities
2. PowerPoint presentation
3. Speaking in public
4. Information kit
5. Letters to the Editor
6. Follow-up

1. Cover letter

» Use your organisation’s letterhead/logo
» Be sure to use the proper form of address and correct spelling of the authority’s name and function
» Remember to identify yourself as a constituent
» Identify yourself as a patient advocate/public health professional, in the text of your letter
» Short letters are best (one page). Don’t use jargon or confusing technical terms
» Concentrate on a single issue. Letters should cover only one topic and be timed to arrive while the issue is alive. State your purpose from the beginning

» Explain how the issue affects other members of the public and how she/he can help
» Include data and references supporting your request (make sure they are accurate)
» Ask her/him what her/his position on the issue is and end by saying you are looking forward to hearing from her/him soon
» If your legislator/health authority helps you by supporting a public health issue, write and thank him/her. Communicate about it via Twitter, the media, etc. This will create further goodwill for future contacts

» Check out government websites for correct titles and addresses
  • UK: http://www.parliament.uk/get-involved/contact-your-mp/contacting-your-mp/
  • France: http://www.gouvernement.fr/premier-ministre/ecrire
  • Spain: http://www.msssi.gob.es/contactar/home.htm

Practical tools
Practical tools

2. PowerPoint presentation

PowerPoint is a presentation software program (Microsoft Office package) in the form of slide shows.

A PowerPoint presentation supports, but should not replace, an oral delivery.

Tips:
- Use key messages
- Include only essential information
- Limit the number of words on each screen. Try not to use more than four bullet points per slide
- Make the most of the layout

- Use titles at the top
- Put most important message up front
- Avoid jargon and overly complex illustrations/data tables, etc
- Avoid: fussy punctuation, too many capital letters, fancy fonts, dark text on dark background, font too small to read at a distance, too many animations and transitions
- Use: photos, simple images, understandable pie charts, impactful (but not distracting) colours

http://www.rarecancerseurope.org/content/download/34991/692747/file/issues-facing-Rare-Cancer-Patients-in-Europe-Bressington.pdf
http://www.rarecancerseurope.org/content/download/37265/726729/file/issues-rare-cancer-research-EU-Negrouk.pdf

3. Speaking in public

- Write notes in a large font (bullet points), not a full speech which you will be tempted to read out
- If you do write a full speech, paraphrase it, do not read it line for line
- Know more about your material than you include in your speech
- Use humour, personal stories and conversational language
- Practice: rehearse out loud, emphasise key messages, find the right flow and speed, articulate (don’t mumble).
  Breathe!
- Project your voice. Don’t speak too fast. Pause where appropriate for good effect or emphasis
- Visualise yourself giving your speech: imagine yourself speaking confidently
- Arrive early: be familiar with the room, microphone and technical aids
- Know the audience, use their names, begin by greeting them and presenting yourself
- Be inspiring, informative and entertaining
- Concentrate on your message (not your nervousness) and your audience
- Be brief and to the point, a long, rambling speech will lose your audience
- Remember to smile and look at your audience
- Remember to repeat your key message at the end of the speech. Think of a good punch line (take home message)

More tips here: http://web.mit.edu/urop/resources/speaking.html

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4. Information kit

Your information kit (presented in a folder or USB key) should contain:

» Your business card
» A cover letter
» A brochure
» Your press release/Presentation in a handout format
» Your mission and history
» Facts, figures and useful links
» Biographies of key spokespersons

5. Letters to the Editor

» Letters to the Editor should be short (around 150 words)
» The writer should offer commentary on something the outlet has recently published
» Before writing a letter, check the publication’s website to see if they recommend word counts or have useful guidelines
» If you are responding to a specific article, include the title of the article in your letter and the date it was published

6. Follow-up

Sometimes authorities or the media need a gentle reminder that you are waiting for feedback. This requires diplomacy.

In the case of media follow-up:

» Contact the editor or reporter you sent your media alert/press release to and try to find out if they will run it. Sometimes your call will make the difference it takes to get your story published
» Pitching is an opportunity to relate to the journalist
» You can do so by email or with a phone call (best)
» By email, you can forward your original mail with a short note such as “Hello Larry, have you had a chance to read this release? I thought your readers might be interested because there will be a public event next week which will be attended by…”
» If you prefer to call, make sure you come across as enthusiastic and confident. You will be interrupting them so start by asking if this is a good time to speak: “Hello Larry, this is Anne from Rare Cancers (your country), is it a good time to speak?”

More tips available here: http://nonprofit.about.com/od/nonprofitpromotion/a/pitching.htm
Following up with authorities

After a meeting or letter, if you haven’t had feedback from the person you contacted, you may follow up by email or letter:

Sample:

Dear Minister,

Our meeting on September 17 proved to be a very productive step toward the implementation of the EU Directive on European Reference Networks in (your country). Nevertheless, we have not heard from you since, regarding the three points we discussed and for which you promised action:

1. Xxx
2. Xxx
3. Xxx

On our side we have contacted the Department of Health, as you suggested and we will be … (explain further actions).

We hope to hear from you before (explain deadline: meeting in Brussels, new legislation, etc). We appreciated the goodwill shown to us during our meeting and we look forward to further collaboration between Rare Cancers (your country) and your government.

Yours sincerely,

XXXX

Press kit

Prepare a press kit when meeting journalists or making an important announcement. It should include background information, facts and figures, where to find more information, your press release(s), bios, images and any other relevant information.

Press release

» Be brief: A press release is one page long (at most two pages!) and should contain short sentences and paragraphs.

» Use the proper format: At the top of the page specify “For Immediate Release” or the date and time for publication (embargo). Also at the top of the page, include the name, phone number, and email address of the person who can provide additional information and be available for inquiries. The last paragraph of the release should include references (if relevant) and a “boilerplate,” which is a brief description of your mission.

» Start with the most important information: The headline should provide a brief but attractive phrase to introduce the information in your release. The headline should grab people’s attention, which often makes the difference in whether or not it will be read. Also include a subtitle under the headline. This gives you the opportunity to add information to hook the reader. A good headline can make the difference between a press release that is read and reported and one that is deleted.

» The first line of your release is the most important; make sure it is effective: The lead paragraph includes: who, what, when, where, and how of the story. If the editor only reads the first lines of a good press release, he/she should have everything he/she needs to get the picture.

» Use simple language: Never use slang, acronyms, or technical terms. If you must use an acronym or technical term, explain it. If using quotes, make sure to have them approved by your organisation’s attributed spokesperson.

» Stick to the facts: Be sure to verify spellings, names, titles, and statistics. A good source for European statistics on rare cancers is http://www.rarecanenet.eu. Avoid comments. Opinions should only be expressed in quotes.

A practical tool

Our meeting on September 17 proved to be a very productive step toward the implementation of the EU Directive on European Reference Networks in (your country). Nevertheless, we have not heard from you since, regarding the three points we discussed and for which you promised action:

1. Xxx
2. Xxx
3. Xxx

On our side we have contacted the Department of Health, as you suggested and we will be … (explain further actions).

We hope to hear from you before (explain deadline: meeting in Brussels, new legislation, etc).

We appreciated the goodwill shown to us during our meeting and we look forward to further collaboration between Rare Cancers (your country) and your government.

Yours sincerely,

XXXX
Sample press release

**Rare Cancers: The challenge of accurate diagnosis - press release**

For immediate release.

Brussels, Belgium - 11 February 2014 - Inaccurate diagnosis is a major obstacle for the proper treatment of patients with rare cancers. A Consensus on Improving the Pathologic Diagnosis of Rare Cancers (1) was presented today by Rare Cancers Europe, together with the European Society for Medical Oncology (ESMO) and the European Society of Pathology (ESP) in Brussels. The recommendations aim to help rare cancer patients get a timely and accurate diagnosis.

The statement is the result of a two-day workshop, where the particular challenges for each type of rare cancer (1) were discussed.

“Inaccurate diagnosis means inappropriate treatment,” said Paolo G Casali, from the Istituto Nazionale dei Tumori, Milan, Italy and ESMO Coordinator of the Rare Cancers Europe Initiative. “Pathological diagnosis is everything in oncology. There is an urgent need for solutions in health organisations across Europe to facilitate referrals in order to ensure an accurate first diagnosis for rare cancer patients.”

Angelo Dei Tos, ESP Co-Chair of the workshop, said, “During this workshop, pathologists and clinicians have worked together to highlight challenges for each type of rare cancer. Diagnosing and treating cancers should always be a multidisciplinary effort.”

Rare cancers affect over four million people in the EU (2) and, taken together, represent 20% of all cancer cases and a huge burden on healthcare.

Zofija Mazej Kukovič, Member of the European Parliament (MEP) and former Minister of Health of Slovenia, said: “When it comes to rare cancers, there is a clear need for European Reference Networks (ERNs). These diseases affect large numbers of people, even though their prevalence is low. Patients have to tackle many difficulties, most of the time without the right support. There is a strong need for more collaboration among experts, especially in small member states. We, the decision-makers, need to work for our patients. The cross-border healthcare directive gives us the opportunity to be more efficient when it comes to rare diseases. Cancer is a distant topic for many of us, but when it comes to our home, things change. At the end of the day, we are all patients.”

Kathy Oliver from the International Brain Tumour Alliance (IBTA) declared: “Every rare cancer patient in Europe should have equal access to the best healthcare. This includes the right to a second (reimbursed) opinion. If the best treatment is not available close to the patient’s home, they should be able to contact the closest centre of excellence very quickly. ERNs are being established under the Cross-Border Healthcare Directive but there is still a lot of red tape. In cancer, timely treatment is everything.”

Industry representatives also attended the workshop. The Rare Cancers initiative has called on them to prioritise the development of medicines for these diseases and will hold another workshop in October to address the methodological barriers to rare cancer care.

Dr. Casali concluded: “We have worked hard on the items for this vital consensus, but the important part comes now. The implementation of the recommendations we will release is crucial to improve the lives of rare cancer sufferers.”

ENDS

References:

(1) Lists and families of Rare Cancers (pdf)
(2) The epidemiology of rare cancers in Europe (pdf)

Notes to Editors:

Rare Cancers Europe (RCE) is a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda and to implementing 39 political and stakeholder recommendations (pdf).

Media alert

A media alert gives reporters information about an upcoming event or activity (press conference, meeting, public event). The difference between a media alert and a press release is that an alert tells reporters about an upcoming newsworthy opportunity that could give them a story to write.

Distributing your media alert

» Send your media alert to “upcoming” or “week-ahead” columns: Look for a phone listing for a news wire service in your city. Wire services include organisations such as the Associated Press (AP) and United Press International (UPI).

» Create a media list: One to two weeks before the event is the best time to email your alert. To get started, develop a current media list. Your list should be up-to-date in order to be effective in reaching reporters and getting them interested in your event.

» Organise your list: see “Tips for working with media” section

» Target the appropriate reporter for your event (i.e. health reporter, or European Affairs reporter, depending on your news). Also find out how far in advance they would like the information about your event.

Tips for following-up

» After you have sent your press release or media alert, contact reporters or editors by phone or email to find out if they plan to cover the event. Sometimes the personal touch can make a difference in creating interest.
Press kit

Sample media alert

Media Alert: Save the Date
To be sent out, for immediate release, on 6 February 2014

IMPROVING DIAGNOSIS OF RARE CANCERS IN EUROPE

Lugano, Switzerland. 6 February 2014. Inappropriate or late diagnosis is a major hurdle for the proper treatment of patients with rare cancers. In order to discuss solutions to improve the pathologic diagnosis of patients fighting these diseases, RARE CANCERS EUROPE, together with the European Society for Medical Oncology (ESMO) and the European Society of Pathology (ESP) have organised a workshop in Brussels, Belgium, on 10 and 11 February 2014.

During the workshop, a Statement on Improving the Pathologic Diagnosis of Rare Cancers will be drafted by a panel of expert Pathologists and Oncologists specialising in rare cancers. The implementation of the recommendations contained in this position statement will be crucial to improve the lives of rare cancer sufferers.

Rare cancers affect over four million people in the EU (1) and – taken together – represent 20% of all cancer cases.

For more information and interview opportunities, please contact Jackie Partarrieu on:
• raredcancerseuropenews@esmo.org
• +41 91 973 19 25

ENDS

References:
(1) The epidemiology of rare cancers in Europe.

Notes to editors:
Rare Cancers Europe (RCE) is a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda and to implementing 33 political and stakeholder recommendations. Visit us on: http://www.rarecancerseurope.org

Fact sheet and FAQ

» Your press kit should include one page with basic facts about the rare cancer you represent and about rare cancers in general
» FAQ is a one pager with frequently asked questions (and answers to them)
  • What is a rare cancer?
  • What makes a cancer rare?
  • Which cancers are considered rare?
  • Where can I find more information?
  • How can I know the diagnosis was accurate?
  • What are the treatment options?
  • Which are the best Rare Cancer centres in Europe?
  • What is the cost of rare cancers to the European economy?

Press conference

» Only for very important announcements or controversial issues which journalists will want to discuss with experts
» Corporate announcements will not attract media
» New science (treatments, devices) will attract press

Giving interviews

» Preparation is essential:
  • Think of the main key messages you would like to get across (three maximum)
  • Bridging: If the journalist leads you to an area you are not comfortable with, acknowledge the question but return the discussion to the message you wish to convey
  • Know your facts and figures
  • Avoid jargon and technical terms. Use simple language
  • Use examples
  • Answer questions directly
  • Keep answers short and to the point (think in terms of headlines)

» Don’t:
  • Say anything “off the record”
  • Say “no comment”. If you don’t know an answer, promise to find out and get back to the reporter
  • Be sarcastic and be careful about humour


Sample media alert

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To be sent out, for immediate release, on 6 February 2014

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  • Where can I find more information?
  • How can I know the diagnosis was accurate?
  • What are the treatment options?
  • Which are the best Rare Cancer centres in Europe?
  • What is the cost of rare cancers to the European economy?

Press conference

» Only for very important announcements or controversial issues which journalists will want to discuss with experts
» Corporate announcements will not attract media
» New science (treatments, devices) will attract press

Giving interviews

» Preparation is essential:
  • Think of the main key messages you would like to get across (three maximum)
  • Bridging: If the journalist leads you to an area you are not comfortable with, acknowledge the question but return the discussion to the message you wish to convey
  • Know your facts and figures
  • Avoid jargon and technical terms. Use simple language
  • Use examples
  • Answer questions directly
  • Keep answers short and to the point (think in terms of headlines)

» Don’t:
  • Say anything “off the record”
  • Say “no comment”. If you don’t know an answer, promise to find out and get back to the reporter
  • Be sarcastic and be careful about humour

Social media

» Why
People increasingly use the Internet to find and share information.

» When and how to use
Where do your members go for information? Spend resources and time to find out where members of your community are most active. The key is creating a social space on the web where people can find information on you and relate to you.

• Twitter: Considered an information network. 200 to 300 million users. Good to check real time information and follow relevant stakeholders. Useful to see what is “trending”. Uncluttered. Messages must be no longer than 140 characters. Use of hashtags (#) before key words helps your information come up when people search your area of expertise. You can post your own information or retweet relevant news from sister associations. Twitter is effective for broadcasting your news and live events such as conferences. Requires regular updating. Use Bitly to shorten links: https://bitly.com. More tips on: http://www.forbes.com/sites/kenkrogue/2013/08/30/31-twitter-tips-how-to-use-twitter-tools-and-twitter-best-practices-for-business/

• Facebook: Considered more of a social network, where people “connect”. 700 million users. Including photos and longer texts, it is a more “curated” experience. Originally used mostly by teenagers, the fastest growing segment today is the 55 to 64 year olds. Needs to be “fed” regularly and you must be ready to spend time interacting with your “friends”. Useful to drive people to your website. Also useful for promoting events, sharing links, enhancing the “word of mouth” effect. More tips on: https://www.facebook.com/business

• Linkedin: A professional network, useful for sharing information or finding volunteers, employees, donors and board members. You can also “follow” other non-profit organisations and learn from what they are doing to promote their causes. Creating a page allows you to post status updates, share news, find volunteers and grow your community. http://nonprofits.linkedin.com

Monitoring

» Monitoring what the press has been saying about you helps you measure how successful your communication strategy has been and identify new opportunities to speak up
» By monitoring we mean counting the number of articles that speak about your organisation and events
» You can do it yourself by setting up Google alerts
  • Go to Google News https://news.google.com (in various languages)
  • Type your key word between “quotation marks”: “rare cancers”, “brain tumours”, “European reference networks”, etc.
  • You will get the current news on the key word you are searching

» At the end of the page you will have the option to set up an alert. Click on ‘create alert’
» You will need to provide an email address where the alerts will be sent to and state whether you want daily, weekly or “as it happens” alerts

» Or you can use monitoring service providers to measure the number of clippings and their publicity value (Cision Point: http://cision.com, Vocus: http://www.vocus.com, Meltwater: http://www.meltwater.com, etc.)
Website

Having a presence on the web is essential so that the public, new patients and their caregivers, potential partners and the media can quickly and easily find out more about your association and the help, services, information and guidance you can offer.

Most patients, and even doctors, now search for information online. Your site is probably the first contact the public will have with your association.

If you want to be taken seriously, the website must look professional and be kept updated.

Do not clutter the homepage, but have relevant tabs that are easy to find and click on. Include information for patients, doctors and caregivers.

Easy to use, free tutorial: http://www.simplewebtutorials.com
FAQ: http://www.simplewebtutorials.com/frequently-asked-questions/

Wikipedia: A comprehensive, free online information source, trusted by patients and physicians, it is good to be referenced here and link back to your website. New patients affected by a disease will look it up and having your patient association referenced under the definition will help them to connect with you. http://en.wikipedia.org/wiki/Wikipedia:About#Contributing_to_Wikipedia

YouTube: Good for sharing video content. For example, sharing patient or doctor testimonials and calling for funds. Also useful to create tutorials. Create an account, a channel and set up key words so people can find your video. Tell stories that haven’t been told. An image is worth a thousand words. https://www.youtube.com/user/nonprofits

Follow-up: Engage with your followers: “like” their comments on your page, answer their questions, retweet their tweets, share their relevant information. This is not a one-way road. Social media is meant for engagement and creating networks.

Monitoring: Check if your communications are being effective by monitoring your results. Facebook, Twitter, YouTube and LinkedIn all offer statistics of how many people have been looking at your posts and whether they have been sharing your news or clicking on your links. Study the posts that were most popular and get ideas of what is working with your audience (meeting their needs). You may also use tools such as sprout social https://sproutsocial.com or hootsuite https://hootsuite.com to help you manage your social media accounts (they are especially useful for scheduling posts at a time when most people are using the networks and statistics on users).

Social media

Links to examples of patient association websites:
http://www.patient.co.uk
http://www.skincancer.org
http://www.macmillan.org.uk/Home.aspx
https://www.cardiosmart.org
http://www.chordoma-uk.org
http://www.gistsupportuk.com
http://www.pawsgistclinic.org.uk
http://www.sarcoma-patients.eu
http://www.ecpc.org
http://www.bhf.org.uk/#&panel1-1
Defining a project

Whether creating a communication strategy, organising a bake sale or a press conference, these steps will help you to get started.

1. Decide on a project name, date of completion and project leader
2. Background: summary of the need (back up with facts and figures), vision, aims, objectives, deadlines
3. Aims: what you wish to achieve
4. Strategy: how you plan to achieve the objectives defined before (methods, scope, partners, etc)
5. Outcomes: deliverables expected at the end of the project
6. Stakeholders: who you will work with and how, what their role will be

Outline for a report

A good project is nothing without a good report. No matter how significant your achievements, if you do not write a clear report of your work (and communicate it), your stakeholders will not get a good grip of what you have done. This may in turn affect credibility and future funding.

It is essential to understand that the report will be read by a number of people, many of whom will not be familiar with the project that the report describes. Stakeholders can’t guess what you have not included in the report.

» Abstract: summary of your work (must be comprehensible to someone who does not know your project)
» Background (scope, setting the scene)
» Objectives – what, why
» Methods – how
» Who did what – stakeholders’ roles
» Results
» Deliverables (measurable objectives): have they been attained? How? How did you measure them?
» Dissemination – how will you communicate your results (Scientific paper, White Paper, Press Release, Meeting, Consensus Document, etc)
» Budget and funding report
» Conclusion: (similar to abstract, but the reader has now read the report. Take home/key messages)
» Next steps
» For more information contact: (name, email, number, website…)

European projects

» European Commission and funding
» Finding an idea
» Submitting a proposal
» Starting the project
» Disseminating the result
» Reporting

The EU provides funding and grants for a broad range of projects and programmes covering many areas, including education and health.

Funding is managed according to strict rules to ensure that there is tight control over how funds are used and that funds are spent in a transparent, accountable manner.

EU funding is complex, since there are many different types of programmes managed by different bodies. Over 76% of the EU budget is managed by member countries. This includes the structural funds – which finance regional policy, social and training programmes, as well as agriculture (including support for farmers).

More information on:

» Beginner’s guide to EU funding (one version for each European language and more information on opportunities for each European country on the European Commission website):
  • http://ec.europa.eu/research/participants/portal/desktop/en/funding/index.html
  • http://europa.eu/about-eu/funding-grants/index_en.htm

Two main types of funding:

» Grants for specific projects, usually following a public announcement known as a ‘call for proposals’. Part of the funding comes from the EU, part from other sources.
» Public contracts to buy services, goods or works to ensure the operations of EU institutions or programmes. Contracts are awarded through calls for tenders (public procurement) and cover a range of areas: studies, technical assistance and training, consultancy, conference organisation, IT equipment purchases, etc.

As a group, the 28 EU Commissioners have the ultimate political responsibility for ensuring that EU funds are spent properly. But because most EU funding is managed at country level, national governments are responsible for conducting checks and annual audits.

Non-governmental and civil society organisations may be eligible for funding, provided they are active in EU policy areas on a non-profit basis.
Resources

Facts and figures on rare cancers

- 20% of all cancers are "rare"
- 500,000 people are newly diagnosed with a rare cancer each year, 30,000 in Europe alone
- 186 cancers types are considered "rare"
- 100% of solid paediatric cancers are "rare"
- 47% is the survival rate for rare cancers, versus 65% for common cancers

Rare Cancers Europe background information

- 39 recommendations:
  http://www.rarecancerseurope.org/content/download/16802/296577/file/ESMO_Rare_Cancers_recommendations_2010.pdf
- Call to action:
  http://www.rarecancerseurope.org/About-the-Campaign/Call-to-Action
- Reports:
  Improving clinical research in rare cancers:
  http://www.rarecancerseurope.org/Events/Past-Events/Rare-Cancers-Conference-2012
  Pathology in rare cancers:
  On patient access to cancer drugs in Europe:
  http://eu.vocuspr.com/Newsroom/ViewAttachment.aspx?SiteName=ESMO&Entity=PRAsset&AttachmentType=F&EntityID=103275&AttachmentID=f60eb64a-e480-48ec-a5ca-b5c9163d3b70
  On the challenges of rare cancers:
  http://www.rarecancerseurope.org/Events/Past-Events/EP-Meeting-Challenges-of-Rare-Cancers
  On orphan drugs for rare cancers:
  http://www.rarecancerseurope.org/Events/Past-Events/EP-Meeting-Orphan-Drugs-for-Rare-Cancers
  The added value of closer cooperation among institutions:
- Consensus Documents:
  On the pathological diagnosis of rare cancers:
  http://www.rarecancerseurope.org/Events/Rare-Cancers-Consensus-Meeting-2014
- Fact Sheet:
  http://www.rarecancerseurope.org/About-Rare-Cancers/The-Burden-and-the-Challenges-of-Rare-Cancers
- Brochure:
Useful Websites

http://www.rarecancerseurope.org
http://www.rarecarenet.eu/rarecarenet/
http://www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines
http://www.patientsorganizations.org/iapo_media/Toolkits/current/iapo_toolkit.html
http://www.eu-patient.eu

References

(1) Rare cancer indicators:
http://www.rarecarenet.eu/rarecarenet/index.php/indicators

(2) Epidemiology for rare cancers in Europe:

(3) Survival for rare cancers in adults:

(4) Comparator report on patient access to cancer drugs in Europe:
http://www.lmi.no/dm_documents/comparator_report_on_patient_access_to_cancer_drugs_in_europe_jan_15_09_wbkfl.pdf