● FACTSHEET 12

Putting gynaecological cancer on national and European agendas

'Working with the Media' toolkit





The European Voice of Gynaecological Oncology

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Adapted for ESGO ENGAGe by Isabel Mortara & reviewed by Peter O'Donnell and Sue Lyon. Layout by Morris and Chapman.

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Introduction

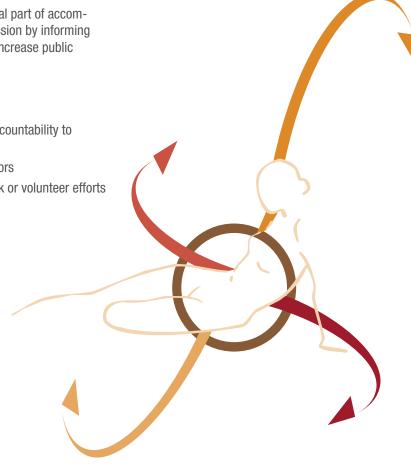
When you think of working with the media, consider that there are paid media and earned media. Most of this guide will discuss details related to earned media. Nonprofits and patient organisations often prefer earned media because of cost factors, but also because as news, the public is more apt to believe when it appears as news. It can also create a more compelling case for information dissemination and engagement. After a brief discussion to help you determine and shape your media approach, we will address paid media first, and then move on to how to build and use relationships to enhance earned media.

Improving media relations and earning news coverage for your organisation is critical to raising awareness of your mission. Media coverage of your organisation's work and leadership helps establish your credibility in the community, attracts allies, and sways public opinion. Your issue and work can grow from something that only a small staff and board discuss regularly to something that families, other boards, and community leaders begin to address.

Working with the media is an integral part of accomplishing a patient organisation's mission by informing the public. Why would you want to increase public awareness? To:

- · Reach out to the public
- · Promote new initiatives
- Demonstrate commitment and accountability to the public
- Engage current and potential donors
- · Bolster your membership, network or volunteer efforts

This toolkit provides useful tips, samples and how-tos to help non-profit volunteers and professionals work with the media to advocate on behalf of their organisation and mission. For those who are new to media work, this toolkit provides the basics for getting started. For those who are more experienced, each part of the resource guide can serve as a checklist for your ongoing efforts to keep the public informed through media.



Getting good media coverage is often seen as a daunting task, but with some preparation and practice it can be a highly rewarding endeavour. A few keys to success are:

- Develop a message or a short set of messages that you constantly refer to and find an interesting slant, e.g. new data, research activity etc. Those messages serve as your guide to answering questions from media, prospective donors, health decision makers, or anyone interested in your organisation, its cause and its programmes.
- 2. When you have something to announce, develop a clearly articulated statement, which has been checked for medical content. The statement should answer:
 - a. What is it that you are reporting?
 - b. Why is it important to the reader?
 - c. How should news be slanted to appeal to target readers and do you have local relevant data?
 - d. When did the news happen?
 - e. Who is your highest level well-known authority to be quoted?
 - f. What are the consequences of the news item?
- Identify one key spokesperson to speak for your organisation (usually the president, board chair, communications or medical director). Having one media liaison makes it easier for the media to contact your organisation (and thus more likely to do so) and helps avoid sending mixed messages.
- 4. Remember, with a few exceptions, the media are not "out to get you". They are people trying to do their job and report the facts on topics about which they are often not experts. They depend on people who are experts on topics to give them the information they need to compile their stories.
- 5. Don't forget to celebrate your successes. When you do get good media coverage, keep a copy for your files, share it with your board, if relevant, and show it to your donors or members or health community leaders in your region and post on your website. Good media can work FOR you.
- 6. Journalists and nonprofits hold a special responsibility to the public. Journalists report on credible information and nonprofits voice soundly-based opinions.. Together, the non-profit sector and the media sustain free and open dialogue and expert opinions.
- Your message competes with many other news items and journalists will make their own evaluation of the 'news' validity of the article.

What Do You Hope To Accomplish?

Before starting a media campaign, you will want to ask yourself these questions:

1. WHAT DO WE WANT? (GOALS)

Is your mission to inform the public of a health issue? Accomplishments? Highlight critical issues and your role in responding to those issues? Gain recognition as the expert in your area of work? Find new donors? Or all of the above? Your goals will inform your message, your target audience and your medium.

2. WHO CAN GIVE IT TO US? (AUDIENCES)

What audience are you trying to reach? Is it donors, members, health community leaders, or the general public? Within those broad categories, do you know audience demographics? Age, gender, ethnicity and location may all play a part in shaping your media choice and messages. You will be most effective in any medium when you know specific details about your audience. Media outlets track the demographics for each publication, station, time and geographic location. You will want to learn of their findings to establish your best market for messaging.

3. WHAT DO THEY NEED TO HEAR? (MESSAGE)

What is the message that you want to convey? Does it relate to your goals? Is it tailored to your audience? Could a viewer or reader explain to somebody else what your message is, after hearing or reading it once or twice?

4. WHO DO THEY NEED TO HEAR IT FROM? (MESSENGERS)

Is it more important for the message to come from your organisation, key community leaders, politicians? Who do you think will carry the most weight and be the most effective spokesperson for the cause? How are you ensuring that they are able to effectively tell your message?

5. HOW CAN WE GET THEM TO HEAR IT? (DELIVERY)

Select the best method or methods to get the word out. A comprehensive, multi-dimensional approach is often best – if possible given time and financial constraints. Recognize that it may take several exposures before it is absorbed by a viewer or reader.

6. WHAT HAVE WE GOT? (RESOURCES)

What resources do you have to make the media outreach happen (financial, the right people to do the talking, information needed, filming or recording capabilities)?

7. WHAT DO WE NEED TO DEVELOP? (GAPS)

Include your communication plans in your strategic and operational plans. You may not have all of the needed resources for a full media campaign early in your nonprofit's life, but by including communications infrastructure in your planning you can increase your ability to be ready when you need it.

8. HOW DO WE BEGIN? (FIRST STEPS)

As in any activity, do not bite off more than you can chew. Start off small, developing messages for your constituents, and expand as trust and impact of your organisation grow. Do not create a negative perception of your organisation by promising activities that you do not have time to complete.

9. HOW DO WE TELL IF IT'S WORKING? (EVALUATION)

Set up a system by which you can track the number of exposures and if there are results from the media. Asking new contacts how they found your organisation is the simplest way to evaluate media exposure. Reviewing the impact of your media investments will inform you of the effectiveness of your communications.

What's News?

Knowing what is news is important in improving your media relations. Keep in mind that not all news items will or should generate a story. Sometimes the goal is to get your patient organisation's news listed in media event calendars, people or announcement columns.

Special Events: Just having an event does not usually constitute a story; there also needs to be a hook – a unique speaker, award winner, milestone, or information about how your event or programme affects the community.

Services and Programmes: Do you keep track of how many people you serve in a year, month, or decade? Is the demand for your services changing? Is this trend tied to an external situation like the downturn of the economy, a change in demographics, or new legislation?

Studies: Does your patient organisation have a study revealing new information about factors impacting your mission? What were the results and how will they affect the community?

Donors and Volunteers: All nonprofits benefit from the support of their donors and volunteers. These individuals typically get involved with nonprofits due to strong personal convictions or experiences. Do your donors, volunteers, patients or survivors have stories to tell about their lives and why they support your patient organisation's initiatives?

Public Policy: Is there a new legislation, policies or regulation being considered that will hurt or help your organisation's members? How will a new national, regional or city budget impact financial resources of organisations such as yours? This type of story can also be an opportunity to educate reporters about the value of a nonprofit or patient organisation as key partners in the health debate.

Campaign: Has your organisation launched a public awareness campaign, succeeded with a new project, or seen a change in gynaecological cancer patterns? When your activities receive coverage, it is important to follow up with the journalist to share the impact and result of your initiative or campaign. Encourage them to write a story about how the money was used. **Partnerships:** Is your patient organisation entering into a partnership with a business, government agency, or another non-profit? What brought the groups together? What were the difficulties encountered during the process? What will the benefits of the partnership be to the community?

Education: Has your patient organisation completed a new strategic plan, launched educational initiatives for health professionals or the community? How will these changes affect the target group and their ability to impact gynaecological cancers? Who will benefit from these initiatives? Is the patient organisation turning a corner in terms of effectiveness? Is there a new trend which may impact increased/reduced prevention, early detection & diagnosis, treatment, rehabilitation or patient care?

Leadership: Has your patient organisation or community recently gained leaders who may impact the health scene? Consider a release about the attributes of these leaders and their aspirations to successfully serve your patient organisation or cause.

Patients: Does your patient organisation provide a service that can help patients deal with their diagnosis and side effects as well as the social environment? Does your patient organisation provide a service that has been shown to be successful? Do you have stories to share of how your work led to improved support?

Pitching Your Story

Now, with everything in place, you are ready to pitch your news or story. If you are just beginning to work with the media, start with lower priority media. You will gain experience in contacting reporters and honing your pitching skills. When you're ready, move on to your top media targets.

You may pitch (or place) a story by calling a reporter or editor directly, by providing the pitch in person, a letter or by email, or by a combination. Many reporters today prefer email. However, a telephone call may sometimes be helpful. If you call, you should ask if they have time to talk because they are often 'on deadline'. Either way, keep it short and to the point. Simply asking an editor to write a story about your cause is not pitching, and in any case you can never assume that media will run exactly what you tell or send them. But if you did your homework up front, you'll know their "beat" and will be able to tie your story into what they write about. Your job is to convince them that yours is a story they must use because it is interesting and newsworthy.

TIPS FOR GENERATING COVERAGE

Build Relationships: Working with the media is about building relationships. The media are usually not experts at subjects they cover – they depend on the people they interview and the research they do to provide them with the information they need. Establish yourself or a spokesperson from your organisation as an expert in your field by reliably providing good information. If an article is run that you wish you had been interviewed for, contact the reporter and let him/her know that if they need a contact on that topic in the future, s/he may call you. When a good story is run or you are well quoted send a thank you to the reporter responsible.

Localize Your Story: How does your story or information relate to the community you are addressing? If you have a release you are distributing countrywide, are there quotes from local people or statistics from different areas that you can include to make it relevant to different areas of the country or region?

Know Your Audience: Who is the audience of the publication you are approaching, i.e. patients, public, women, young women, etc.? In general, avoid using excessively long words (like "excessive"!); write simply and clearly.

Tie to Current Events: Pay attention to local, national and international events in the media. If the media are closely covering stories about an issue that is related to your mission or programmes, send a press release about your patient organisation or cause and how it is related to the issue, or call the media covering the story and offer to serve as a local resource on the issue.

Avoid Jargon and Acronyms: Nonprofits are notorious for jargon and acronyms. Keep your message easily readable by avoiding terms and acronyms that most people do not know. You and your friends know what a term means, but don't take for granted that others will also. If there is any doubt, either find another word or briefly define its meaning.

Build on Success: If you have had success with a story, you can strategically use that success to spin more coverage. If you got coverage about a programme you have initiated, you may be able to follow up with the same media outlet, or another one, about future developments.

Use Media Wisely: It is good to generate media coverage on a regular basis; but it is not good to overwhelm the media. Sending regular press releases is good, but don't send them so frequently that people get sick of them and quit reading them. Make sure every communication justifies itself with content that could reasonably be assumed to have some importance to the recipient. Take advantage of media opportunities in addition to press releases. Many news outlets now have online forms you can fill out to list events in calendars – some won't even take calendar announcements submitted any other way.

Distributing Releases: Some media still prefer to receive releases as faxes, some even prefer mail, but many, especially in print media, prefer to receive releases via email. If you are sending a press release via email, be sure to use a catchy subject (use your title for ideas) and paste the text of the release in the body of the email. Do not send it as an attachment. You want the reporter to open the release, quickly be able to determine what it is about, and want to read more. See the "Creating an Effective Press List" section for more tips on distribution.

TARGETING MEDIA

Once you have analyzed what is newsworthy about your organisation and you have developed supporting messages, you'll want to map them against your target media. First, assemble a complete list of individuals you want to contact at various media outlets in your community. If you need help, your city's website may have a list of media that serve your region. Consider all options: community newspapers, regional newspapers, health/women magazines, business magazines, urban dailies, TV and radio stations, online news services and blogs, and wire services.

Using your list of potential media outlets, plug them into a grid. Match your messages with media outlets by doing a little research on what they cover. You will find this by looking on the web or by visiting your local library or bookstore. You will increase your chances for coverage by knowing which types of stories the publication or media outlet is likely to handle and which editors are responsible for which pages.

An example:

Message	Media
Feature story idea	Local newspaper: print and web-based; trade publication; regional magazine
Community event with great visual	Local TV station; radio prior and during; perhaps a radio station would set up shop throughout the event.
Personnel changes	Newspapers
Information about upcoming meetings or events	Newspaper & radio calendars
Synopsis of speaker remarks at a community programme	Newspapers, web, regional magazine, trade publication

TIP



Informing the press of an event where a patient organisation representative/leader is speaking or sending a synopsis of remarks afterward is an excellent way to reinforce leaders in your organisation as experts in a particular topic. Helping reporters gain access to your local leadership will also help build reputation and relationships.determine what it is about, and want to read more. See the "Creating an Effective Press List" section for more tips on distribution.

Who Does What?

With individual variations, almost every newspaper and magazine, radio and television station has the following sort of editorial line-up. Use it as your guide to "pitching" your idea.

BROADCAST

There are many radio and television channels. Broadcast news segments should be short and simple and sometimes based on sound bites from several sources. Some longer programmes allow more extensive coverage, and seen for people to call in with questions or comments.

WEB PORTALS

Press releases and articles should be published on the association website but can also be sent to partners with a request to post with a link on their website.

DAILY NEWSPAPERS

Editor, managing editor or executive editor: Determines overall editorial stance of the newspaper (in conjunction with editorial page personnel) and the general thrust of news gathering.

News editor: Makes day-to-day decisions on what to cover and who will do it. Can refer you to the reporter who covers health.

Editorial page editor. Writes some or all editorials. Supervises any other editorial writers and those responsible for selecting op-ed pieces and letters to the editor. **Sunday editor:** Assigns and oversees feature articles and other soft news in the Sunday paper, including sections on art, entertainment, lifestyle, nature, outdoors, sports, and travel.

Features editor: Assigns and often writes human interest stories.

Lifestyle editor: A good prospect for stories on people in your organisation who are doing interesting things – and frequently covering health-related issues too.

Columnist: These may be generalists, but many have special interests, such as the environment, politics, or the arts.

Issues reporter: Specialises in a particular field, such as health, energy, education, labour, medicine or government.

Feature writer: Specialises in stories about people (human interest stories).

Correspondent: Covers a region in the outlying circulation area of a newspaper.

WEEKLY NEWSPAPERS

Editor: In addition to traditional duties, usually writes editorials, some stories, and maybe a column.

Correspondent: Reports on your town or region.

Columnist: May also be the editor.

TELEVISION AND RADIO **Executive producer:** In charge of a particular programmes or series of programmes.

Producer: Responsible for certain segments of a news programme or a specific programme in a series.

News director: Responsible for overall tone and content of news programmes and, at smaller stations, assigns crews to stories.

Assignment editor: At larger stations makes day-to-day decisions on what to cover and who to send.

Station manager: At smaller stations sets policy on news coverage and supervises overall operation.

Programme director: May determine content and select participants of talk shows (or you can deal directly with the talk show host.)

Public affairs director: In charge of public service announcements (free commercials) that you provide, usually aired during off-peak hours. Establishing Your Message

Contacting the media is not about just getting your name printed, your voice aired, or yourself filmed. It is about presenting a message, an opinion, or a fact that you think will make a difference in how people think about your cause. Media relations efforts need to begin with clearly articulated statements. Your answers to the five Ws are essential to defining your story,

THE FIVE W'S

- 1. Who are you? Who do you represent? This should be a concise organisation description.
- What is the news you want reported? When answering this question think carefully about what you want this story to accomplish. Are you inviting people to

an event, are you communicating an important fact, or are you stating a position on an issue?

- 3. When will the event occur?
- 4. Where will the event occur?
- **5.** Why is this news report important? Why should others care about what you are doing?

HOW TO ESTABLISH YOUR MESSAGE (SAMPLE)

You can use this grid to help craft your messages.

 Local newspaper: print and web-based; trade publication; regional magazine
 A media toolkit assists patient groups to mobilize greater public awareness about prevention, detection, diagnosis, treatment and care.
• The toolkit covers topics such as what makes good news, how to pitch your story, tips on working with the media including television, radio and print, how to write a press release, media advisory or op-ed and how to organize a press conference.
• The media toolkit will be launched at the 2 nd ESGO Patient Seminar during the ESGO conference, 19 October, 2013 in Liverpool.
 Patient organisations face many challenges in raising aware ness about cancers of the womb, ovary, cervix as well as rare cancers affecting the vulva, vagina and fallopian tubes. These 'silent' cancers do not attract enough attention from the public and policy makers or from women themselves. The symptoms may be sometimes vague or women may be too embarrassed to talk to a doctor and wide inequalities exist across Europe depending on where patients live and are treated.
• The reticence needs to be overcome and a more posi- tive message developed to improve prevention, screening, treatment and care of patients with gynaecological cancers, so that women throughout Europe have the best chance of survival and quality of life.
• Patient groups have an important role in raising awareness about gynaecological cancers, the gap between what we know and what we do, and the continuing inequalities both between an within European countries documented in the <i>State of gynaecological cancers in Europe</i> also released during the seminar.
 Groups coming together as one voice in Liverpool is incredibly important in educating the public, policy makers with and through the media.

Working with the Media

Top 10 Media Relations Tips—and More

By Brad Elman, reprinted from Ask.com

It takes considerable time and effort to develop solid media relationships. In turn, good media relationships will help you get your name recognized, and people will think well of you and what you do because you have—and deserve—a favourable reputation. The following is general etiquette for building good media relationships:

- 1. Know your media. Become familiar with the columns in your local newspapers and periodicals, and the news and talk programmes on TV and radio.
- 2. Meet deadlines. Every reporter has a deadline to meet, so be aware of them and do your best to accommodate the reporter's request in a timely manner. They will appreciate it and remember your cooperation when the next opportunity develops.
- 3. Be helpful. Help the reporter as much as you can. The more facts and statistics you provide the better, since they often don't have time to do all the research themselves. Feel free to ask questions or offer any information they might need.
- **4. Be accessible.** As you begin working with local reporters, tell them you are available if they need

help with the story. Ideally, you want to be a resource the next time they work on an gynaecological cancerrelated article.

- 5. Make incoming media calls a priority. A reporter's call should be returned within the hour, even just to let them know you received the call. Alert your team or office to this priority.
- 6. Keep promises. If you ever give a newspaper exclusive rights to publish your news, stick to your word. If you promised to get back to a reporter, follow through. You will quickly lose credibility with the news media if you forget about promises.
- 7. Be a gracious host. When a reporter arrives at your home or office, meet and greet them. Cater to their needs; give them a quick overview of your business;

offer interview or photo opportunities and see if they have questions.

- 8. Don't get angry. The resulting story may not be exactly what you had hoped for. Call and correct any inaccurate information and clarify confusing points without getting angry. Even if the story is not reprinted, the corrected information will go into their files.
- 9. Don't ask to see the story before it goes to print. Reporters are not receptive to requests for editorial approval, but an editor or researcher might call you to double-check facts.
- **10.** Always be courteous, honest and accurate.

YOUR RIGHTS

While you want to want to bend over backwards to maintain positive relations with the media, you should be aware of your rights. You have the right to:

- Understand the story that is being written
- Represent your side of the story
- Ask for correction if the story is inaccurate and receive that correction
- . Go to the editor if you can't solve problems with a reporter
- Request an opinion piece if your view isn't represented

TIPS for Television Interviews



Television is one of the most powerful communications tools. Because it is a visual medium in a visual society, TV has its own set of rules. You will be more effective if you know the format of the programme and what stories have recently aired, so watch the show for a few days prior to your appearance. To use TV effectively, keep the following in mind when you are being interviewed:

- 1. Wear a dark suit and light colored shirt; this looks best through the camera lens. Avoid patterns and bright colors; they tend to distort your appearance.
- 2. Avoid dark glasses and thick, dark frames.
- **3.** Sit or stand straight and look at the reporter, not at the camera and not at the floor. Keep your voice at a normal speaking level; if you are not being heard, you will be alerted.
- 4. Don't waste response time by repeating the reporter's questions.

TIPS for Print Interviews

The key to a successful print interview is to maintain your focus. Prepare, practice and remember the messages you want to get across. Always remember what you are there to accomplish. Here are a few tips to help you prepare for your interview:

- **1.** Ask the reporter for information that will help you prepare for the interview. What type of story is being written? What is the angle? Are others being interviewed for the same story? What is the reporter's deadline? What is the reporter's background?
- 2. Most reporters have anywhere from 15 minutes to five days to gather information and write an article. If it is not a breaking news story, the reporter may have more time to complete the assignment. Don't hesitate to ask the reporter when the story must be filed. In addition, do not be afraid to tell a reporter that you would like time to assure accuracy and precision in your information.
- **3.** Know what you want to say and keep your responses brief and direct. Conduct background research on the topic and be prepared for unexpected and difficult questions.

TIPS for Radio Interviews

A tape recorder and a microphone are a radio reporter's main tools. If the interview is live, your microphone is the only thing between your voice and the public's ear. Radio is a fast medium, so keep your answers short. Here are a few other things to remember:

- 1. If you're on a radio spot, open with an attention grabber* to capture the listeners' attention.
- 2. Always be conversational and quotable, but be careful.
- 3. Try to be smooth from beginning to end. Do not say "um" or pause for too long.

In preparing for the interview, request knowledge about the specific questions you will be asked on air prior to recording so you can offer the best information possible to the station's public. Be prepared for any questions related to the topics you've been given, or any topics that are breaking news. It's much better to over-prepare. If you don't know the answer to a question asked when on the air, be frank about not having the specific details and offer to get back to the reporter, or station, with that information at a later time.





How to Write an Effective Press Release

A press release is brief and highlights an important event, decision, or piece of information. The first paragraph of a press release should include who, what, when, where, why and sometimes how. Make verbs active and the subject concrete. Cover the most important facts first and follow with details.

Give your press release a catchy title, e.g., "New gene linked to ovarian cancer." Write the heading as if it were the headline you'd like to read in the paper. Write a first sentence that makes it tough to stop reading.

Be sure to include a contact name and telephone number on the top right corner. List a number that will be answered by a live person – even if that includes mobile, home and work numbers.

Don't forget to include the date of your release on the upper left corner of your release. Write "FOR IMMEDIATE RELEASE: Month day, year." Include a quote from your spokesperson. Be sure to use his/ her title and the full name of the organisation. Sentences in quotes should be short and to the point. It is a good idea to alert your spokesperson about the release and their quote so they are not caught off guard.

Write in the third person. Using the first person will make your release more like promotional material than news.

When writing your press release, you may find it helpful to follow the usage, spelling and punctuation style guide of a major news organisation in your country or region; e.g. the BBC News style guide (http://www.bbc.co.uk/ academy/journalism/news-styleguide). At the bottom of page one write "more" if necessary, otherwise write "end" or use the symbol "###"centered below the text.

Limit your release to one or two pages. Reporters hate getting long faxes/e-mails. If you need to include more information and facts, add a weblink, or indicate that further information can be sent on request.

If a major event warrants an immediate and lengthier response from your organisation than a press release, write a one-page statement from your president. Use the title: "Statement by (president), President of the (nonprofit)."

Proof everything at least twice. If your press release looks disorganized and is badly written, journalists will tend to ignore it, and the nonprofit's image will also suffer. Conversely, if the release is well written, the paper may use it (or at any rate part of it) verbatim.

Never editorialize in press releases. For example, do not write that a speaker is gifted. Keep opinions and judgments within the quotes.

After sending your release, make follow-up calls to specific reporters, making sure they received your release. But be judicious about this. It can be very counterproductive.



Press Release Template

Print your press release on letterhead

ESCO European Notwork of Gynaecological	
Organisation	
FOR IMMEDIATE RELEASE: Month day, Year	CONTACT: Name, Title
or NEWS RELEASE (if not timely)	Phone Email
Headline – One or two lines that capture the essence of what you want to say	
the essence of what you want to say	
Subhead – A line of support or another level of intr	igue.
"Follow up with a quote as soon as possible," Jones said in the first paragraph, just use their last name and don't	 If the quote is attributed to the same person introduced repeat the title.
Support what you said in the first paragraphs with more up and make the point stronger.	about why this article is relevant and any facts to back it
If the release goes to a second page, make that known I	by
MORE	

HEADLINE SUMMARY

Date

Page 2

At this point in the release, support information can be given in bullet form if that makes it easier to read at a glance.

A news release should never be any longer than two pages. If it is, you can:

- Make sure everything in the release is relevant and important. Otherwise, cut out the fat.
- Take some of the support information you feel is important and include it in a second piece, like a fact sheet or by-the-numbers sheet.

Photo Opportunity

If there is a photo opportunity with this story, make it known.

Boilerplate – Short paragraph that includes information about your organisation (when it was founded, what it does, hours of operation, contact information again, web site.) The same text should be included in every release you do.

About the Patient Organisation

The organisations mission is to.... Major projects include (list projects, activities etc). The Organisation is located at (add address details). The Phone number is (list number) or toll free (list number). The Web address is www.----.org.

Let the reader know the release is over by...

###END###

Sample Press Release



PRESS RELEASE: Wednesday 4 September 2013

Scientists find new gene linked to ovarian cancer

Cancer Research UK Press Release



Cancer Research UK scientists have found a gene in mice that could protect against ovarian cancer and, if faulty, may increase the chance of developing the disease, according to research published in *Nature*¹.

This gene, known as *Helq*, helps repair any damage to DNA that happens when it is copied as cells multiply. So if the gene is missing or faulty, DNA errors could mount up, increasing the chance of cancer developing.

The team, from Cancer Research UK's London Research Institute, found that mice without either of the two copies of the *Helq* gene were twice as likely to develop ovarian tumours, as well as becoming less fertile. And even losing just a single copy of the *Helq* gene was enough to cause a mouse to develop more tumours.

Dr Simon Boulton, senior author from Cancer Research UK's London Research Institute, said: "Our findings show that if there are problems with the *Helq* gene in mice it increases the chance of them developing ovarian and other tumours. This is an exciting finding because this might also be true for women with errors in *Helq*, and the next step will be to see if this is the case.

"If it plays a similar role in humans, this may open up the possibility that, in the future, women could be screened for errors in the *Helq* gene that might increase their risk of ovarian cancer."

Dr Julie Sharp, Cancer Research UK's senior science information manager, said: "This study pulls together clues from a series of experiments building a picture of cell faults that could lead to ovarian cancer in women.

"Ovarian cancer can be hard to diagnose early and treat successfully so the more we know about the causes of the disease, the better equipped we will be to detect and treat it."

In the UK around 7,000 women are diagnosed with ovarian cancer each year and around 4,300 die from the disease².

ENDS

For media enquiries please contact the press office on 020 3469 8300 or, out-of-hours, the duty press officer on 07050 264 059.

Reference

Adelman C.A., Lolo R.L., Birkbak N.J., Murina O., Matsuzaki K., Horejsi Z., Parmar K., Borel V., Skehel J.M. & Stamp G. & (2013). HELQ promotes RAD51 paralogue-dependent repair to avert germ cell loss and tumorigenesis, *Nature*, <u>DOI: 10.1038/</u> <u>nature12565</u>

Notes to editors

² For more information on ovarian cancer cases and deaths in the UK, visit http://www.cancerresearchuk.org/cancer-info/cancerstats/types/ovary/incidence/

How to Write a Media Advisory

A media advisory functions as an FYI (for your information) that alerts journalists to an upcoming event. It gives the basic information: who, what, when and where.

A media advisory "what" is much like a news release headline. Clearly state the news here with a short description of the event and the issue.

List the speakers at your event. Explain who will speak and what they will discuss.

Say when the event will take place. Include the date and time.

A media advisory "where" provides the location name and address.

Directions may be necessary if the event is held in an obscure location.

The contact should be the person who will speak to the media or facilitate interviews. This person must be easily accessible. Place the contact information in the top right corner of your media advisory.

In the top left corner, type "Media Advisory." Beneath that, type the date.

Include a short summary of your organisation in the last paragraph.

Mention "Photo Opportunity" if one exists and be sure to send it to the photo editors of local news outlets as well as to reporters – they don't always share information with each other!

Type "###" at the end of your advisory. A media advisory should never be more than one page.

A media advisory should arrive 3 to 5 working days before the event. Fax or mail (if time permits) your advisory to the appropriate reporter, editor or producer at each news outlet on your press list.

ALWAYS make follow up calls the day before your event and have the advisory ready to be faxed or emailed.



Sample Media Advisory



MEDIA ADVISORY

WHAT	The Patient Protection and Affordable Care Act (P.L. 111-148) included a groundbreaking provision requiring coverage without co-pay of women's preventive services. These services will be determined through the Institute of Medicine, via the Health Resources and Services Administration, based on scientific evidence.
	The Ovarian Cancer National Alliance recommends that oral contraceptives and prophylactic or risk reducing bilateral salpingo-oophorectomy be included as preventive services necessary for the health and well-being of some women.
WHY	There are two evidence-based methods of preventing ovarian cancer:
	1. The use of oral contraceptives
	The use of oral contraceptives has been proven to reduce the risk of ovarian cancer by 50 percent if taken for five years. ¹
	Other studies have shown that for women with a genetic mutation, the risk reduction in taking oral contraceptives is 13 percent per year, and 6 percent per year for women without the mutation. ² Another study showed a 5 percent decrease in the risk of ovarian cancer for each year women with the genetic mutations took oral contraceptives. ³ A meta-analysis showed an additional 36 percent reduction for each additional 10 years of use. ⁴
	There is some concern about the increased risk of breast cancer for women taking oral contraceptives. One study showed no increased risk of breast cancer for those using oral contraceptive formulas developed after 1974. ⁵ Another study showed a slight increase risk of breast cancer which disappeared after five to ten years of stopping oral contraceptive use. ⁶ These risks should be weighed by a woman and her health care provider.
	2. The removal of the ovaries and fallopian tubes (prophylactic or risk-reducing bilateral salpingo-oophorectomy)
	For women at high risk of developing ovarian cancer – those with a family history of certain cancers or with genetic mutations – risk reducing salpingo-oophorectomy (RRSO) has been shown to reduce the risk of developing ovarian cancer by up to 85 percent. ⁷ One meta-analysis showed that the surgery reduces the risk of breast cancer by 50 percent and ovarian cancer by 80 percent. ⁸
wно	The Ovarian Cancer National Alliance is the foremost advocate for women with ovarian cancer in the United States. To advance the interests of women with ovarian cancer, the organization advocates at a national level for increases in research funding for the development of an early detection test, improved health care practices, and life-saving treatment protocols. The Ovarian Cancer National Alliance educates health care professionals and raises public awareness of the signs and symptoms or ovarian cancer. The Ovarian Cancer National Alliance is a 501 (c) (3) organization established in 1997.
NOTE	According to the American Cancer Society, approximately 21,000 American women are diagnosed with ovarian cancer each year, and approximately 15,000 women die from the disease annually. Ovarian cancer is the deadliest gynecologic cancer and the fifth leading cause of cancer death among women in America. Currently, more than half of the women diagnosed with ovarian cancer die within five years.
CONTACT	For more information or to schedule an interview, contact Georgi Morales with Ovarian Cancer National Alliance at (202)331-1332 or via email at <u>gmorales@ovariancancer.org</u> .

http://www.ovariancancer.org/wp-content/uploads/2009/06/2010.12.8-Womens-Preventive-Services_media-advisory_FINAL.pdf

Creating an Effective Press List

Include major newspapers in your area. Consider the media source's audience(s). Make sure that your media list includes all of the audiences you are trying to reach, i.e. local audiences, regional audiences, young people, patients and families, different ethnic communities. Remember, your target audience may change depending on the nature of the releases you distribute.

Get a list of regional and local specialty publications/magazines

that might be interested in your project.

Monitor the media relevant to your organisation and keep an updated list of reporters covering your issues. Look for bylines and add them to your press list. Update your press list on a regular basis.

Include television and radio stations with news and current event talk shows. For broadcast news shows, send a release to the specific reporter covering your issue, or to the senior producer for smaller stations. For talk shows, send to the producer. Target drive time – early morning shows or late afternoon/rush-hour radio shows.

Check to see if you have a local wire-service bureau in your area that would help distribute releases. A couple of large wire services include PR Newswire, www.prnewswire.com, and Business Wire, home.businesswire. com. Euractiv also has a press release service (euractiv.com)

Helpful information to have in your media contact list

- Company
- Website
- Contact name, title
- Contact preference (email/fax)
- Type of contact (calendar, society, columnist)
- Media category (TV/Radio/etc.)
- Address

- Phone
- Fax
- Email
- Language (English/Spanish/Swedish etc.)
- Distribution/Reach (city/region/national)
- Focus (general/business/youth/etc.)
- Audience (age/gender/etc.)

Include relevant university newspapers, church bulletins and nonprofit newsletters.

Be sure to send your press release to the newswire daybooks. Major news agencies in Europe have daybooks, which are wire printout listings of times and locations of each day's press events. Send your press release at least two days in advance. Make a follow-up call to ensure it will be listed. For a list of European news agencies, visit http://www.newsalliance.org Send notice of all events to newspaper community calendars.

Verify that you have proper contact names (e.g., assignment editor, health care reporter, community/ lifestyle reporter and editorial writer). Obtain correct spelling of names, telephone numbers, email addresses, fax numbers and addresses for background mailings. Media professionals like receiving information in various formats. While many now prefer receiving press releases via email, others still prefer fax or mail. Be sure to note in your press list the best way to contact them.

Find media contacts searching the web for "health media" or asking cancer/health/patient/women's health nonprofits with similar missions to share their lists.

Preparing for a Meeting with an Editorial Board

The purpose of editorial board meetings is to establish a good relationship with your local and regional media. They might not agree with all of your positions, but they should know who you are and respect your work.

Another important goal of such meetings is to encourage the outlet to cover an issue or campaign of yours, or even provide editorial support for a campaign. The editorial board also could decide to publish a Q&A based on their discussion with you at the meeting.

Call the senior editorial writer at your regional or local newspaper or other media organisation a week to ten days in advance. Tell her/ him that you would like to talk with the editorial board to discuss your group's issue priorities, project or campaign. Time the meeting around your project or key action in the Legislature. If the editor is not keen on an editorial board meeting, suggest that you send her/him a press pack on the issues or event that you would like to discuss and make a follow-up call. Get the editorial writer's direct phone number, fax number and mailing address. If the paper is small, suggest a meeting with the paper's publisher or editor, or an informal get-together over coffee or lunch.

Find out what positions the newspaper's editorial board has taken on your organisation's issues. Get copies of those editorials from the newspaper's librarian. Read them carefully before the meeting.

Before the meeting, arm yourself with useful facts and figures. Don't be intimidated. They want to hear what you have to say.

Limit the number of people you bring to the editorial board meeting to two or three. Reconfirm the meeting one day before. Send your nonprofit's president with your project manager or issue expert. Be sure to leave your business cards, with contact phone numbers.

Prepare an agenda for the meeting. List the points or issues you would like to cover. Distribute the agenda and fact sheets on your group's campaign or issues at the beginning of the meeting. Explain why you are there and why your issue or campaign is important. Invite questions from editorial board members during your presentation.

Make a follow-up call after the meeting to find out if the media outlet plans coverage, or to run an editorial. Be sure to get a copy if it does. If the paper runs a negative editorial, ask for space to place an opinion editorial, or op-ed, stating your position.

How to Write and Submit a Letter to the Editor

The letters-to-the-editor section is one of the most widely read sections of any newspaper. Letters to the editor are usually written in response to an article or editorial published earlier in the newspaper.

If you see an article or opinion piece that presents a position that is opposite your group's, write a letter to the editor disagreeing with the article and stating your organisation's position. If you don't disagree but have a different perspective, that too can be the basis of a letter to the editor.

Call the newspaper and ask to speak to the "letters-to-the-editor" department. Ask how long the letter should be. Find out the name, fax number and mailing address of the person you should send it to.

In the first paragraph of your letter, refer promptly to the article or position that you are writing about. Name the reporter who wrote the article and the date and the title of the article. State why you disagree and proceed to give your group's position on that particular issue. Short and pithy is better than long and rambling.

Send a cover letter addressed to the appropriate editor. Attach your business card. Be sure to sign the letter with your name, title, and the name of your organisation.

How to Write and Submit an Op-Ed

Opinion-Editorials, also referred to as Op-Eds, are opinion pieces a publication's reader writes and submits to a newspaper or magazine on a topic relevant to the publication's audience.

Learn the name of the newspaper's op-ed page editor and the length specifications for op-eds and the address or fax number. Most are 700-800 words long, so you need to be succinct in your writing.

Monitor your paper's op-ed page to see what kind of op-eds it publishes. If the paper recently ran a piece on a position that your non-profit disagrees with, you might have a better chance of getting your organisation's position in print.

There should be a compelling hook to generate interest in the op-ed and demonstrate its relevance to the readers and the community. Give it a strong local angle. The reader needs to be able to relate quickly and easily to your story.

Decide what message you want to convey. Write it in a brief sentence. Decide the key arguments supporting your message and develop each in turn.

Have an opinion and state it forcefully. Make your case from the top down. Begin with your opinion and then back it up with facts. Don't present facts first and save your opinion for the conclusion.

Print your op-ed on your organisation's letterhead and sign your name and title.

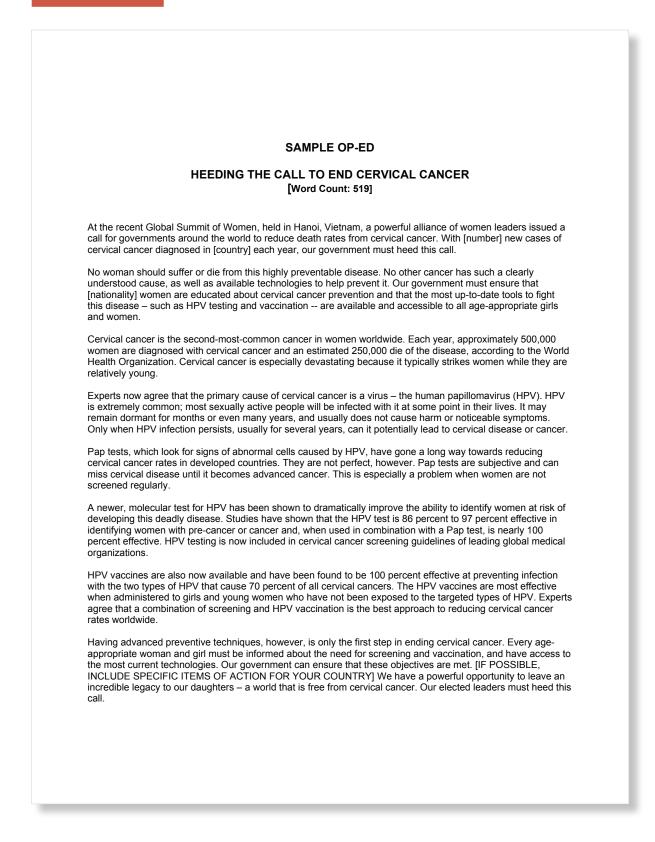
Send your op-ed with a cover letter and background information on your non-profit to the op-ed editor. Include your business card with both home and work numbers. Make a follow-up call a day or two after the editor has received your op-ed. Ask if the paper intends to print it. If so, find out when. Get a copy.

Op-ed Questions

Prior to writing an op-ed, answer the following list of questions to ensure that you make the necessary points for an effective piece

- What is the problem in the community that your organisation is solving?
- How does your organisation help to solve this problem?
- · Describe your organisation. How does it work?
- . Why wasn't the problem solved before? What was the obstacle?
- Is there a villain in the story?
- . What is the cost of the solution you propose?
- How can you "paint a picture" in someone's mind through your words?
- Which community leaders, groups or people in the community agree with you? Why?
- Which community leaders, groups or people in the community disagree with you? Why?
- What is the urgency?
- Who does this affect?
- What is the history of this story? What has been done before? What was the process to get to this point? Was there a cliffhanger or suspenseful event?

Sample Op Ed



http://www.globalendcervcancer.net/system/files/Sample+Op-Ed.pdf

How to Respond to Questions from the Media

If you do an excellent job submitting your story, reporters will be interested in learning more. Here is how you effectively answer their guestions.

When a reporter contacts you, reply immediately. Be prepared to ask them:

- What is your deadline?
- What questions do you have?
- Who else have you contacted?
- · Know your message.

It is important that everyone in your group is clear about the message being conveyed. Have your message points written out and practice saying them before being interviewed.

Your message is where your expertise lies.

Your response to any question should tie back into your message.

If you know that an issue has come up where you might get calls from the media, prepare yourself by making up questions that the media will most likely ask and answering them in ways that tie back to your organisation's message.

If you have initiated an interview with a member of the media, provide the interviewer with a fact sheet including information you would like to share and even suggestions of questions he or she could ask. The interviewer might not stick to what you gave them, but providing them information in the beginning will increase your chances of being able to cover the information you want to cover. Generally, the interviewer will appreciate your time preparing for the interview.

- If you are able to schedule an interview, prepare yourself through role-play.
- Make up some questions that you would expect a reporter to ask.
- Answer those questions and familiarize yourself with them. Do not forget to tie in your message.
- Have a partner repeatedly ask you those questions so you can practise answering and better prepare yourself for the interview.
- · Do not be afraid to say you do not know.
- If you are unable to answer a reporter's question, refer him/her to someone who can, or offer to research the question and get back to him/her. If you take the second approach, be sure to follow up quickly.
- If you realize you stated an incorrect fact or misstated your thoughts, immediately let the reporter know.
- Provide any information that you may have for an upcoming story.
- Reporters appreciate the gesture and this helps to build connections with media outlets.
- Building rapport with a reporter will give you a better opportunity to frame your story for the public.

Preparing for and Giving Great Interviews

Never go to a media interview without reading that morning's newspapers. You should be very well informed.

Be sure to watch or listen to the programme or host who will be interviewing you before you appear. Get to know the style and format of the show.

In some cases, it is good to send some questions for the reporter to ask you or preparatory fact sheets to the reporter prior to the interview. This will make it easier for the reporter to interview you and help you make a good impression by being well prepared.

Focus on no more than two or three major points to make during the interview. For each point, be sure to have two or three good facts to back it up. Don't let the reporter's questions get you off track. Keep coming back to your major points. Don't forget the reason you are there. Listen carefully to the reporter's questions. Always answer by coming back to the main points you want to make. Never answer with a simple yes or no. Never say "no comment." It makes you sound guilty. The easier you make it on the reporter, the more likely she/he is to have you back.

Maintain good eye contact with reporters. Speak clearly and distinctly in a normal conversational tone. In TV interviews, ignore the camera.

Don't use technical jargon or acronyms. Be friendly. Avoid long sentences. Remember, you want to be quoted.

Never get upset or lose your temper with a reporter. You want the media on your side. Maintain a sense of humour. If the reporter is antagonistic, use your charm. Keep cool.

Remember, you represent your organisation. Don't give personal

opinions that might compromise your group. Never go "off the record."

You have a serious message to deliver. Don't wear clothes that are too flashy. Stripes, checks and white are not good on TV. Don't wear dangling jewelry. Don't fiddle on camera. Assume microphones are on at all times. Assume you are on camera until they tell you that you're not.

Remember, you know more about your issue than the reporter. You've got the upper hand! If the reporter wants facts and figures you don't have – tell her/him that you'll find out the information and go back to making your important points. If you are not sure about a fact or figure, **don't use it!** You want the media to rely on you as a reliable source of nonpartisan facts.

If possible, try to obtain a tape of your performance. Review it. Get a friend to critique it. Correct your mistakes in the next interview.



Checklist for Press Conferences

One week before your press conference: Arrange for a room that is not so large that it will look empty if attendance is low. Sites may include hotels, local press clubs or public buildings near media offices.

Check on:

- Podium standalone
- Speaker system if needed
- Screen and projector for slides if needed
- Microphone stand on podium
- Backdrop blue if possible
- Chairs theatre style, large centre aisle
- Easels if needed
- Electricity outlets for TV lights
- Table for media sign-up and materials
- Water for participants

Pick a convenient date and time. Tuesday, Wednesday or Thursday is best. However this may vary from country to country. Try not to schedule before 10:00 am or after 2:00 pm.

Send out written announcements by fax, email, mail or hand deliver to: • Editors

- Luitors
- Assignment desks
- Reporters
- Weekly calendars

Prepare written materials, including written statements and press kits. The day before:

- Formalize the order of speakers and who will say what
- Call all prospective media and urge their attendance
- Double check the wire service daybooks
- Collate materials and make extras for follow-up

- Walk through the site and review details
- Type up names and titles of spokespeople for media hand-out

That morning:

- Make last-minute calls to assignment desks and desk editors
- Double check the room several hours before
- Walk through the press conference with principal speakers

During the press conference:

- Have a sign-in sheet for reporters' names and addresses
- Give out press kits
- Hand out a written list of participants
- Make opening introductions
- Arrange one-on-one interviews if requested

Checklist for Press Kits

It is not necessary to send a press kit every time you have information to share. A press kit is a useful tool for introducing your organisation to a member of the media. It can also be helpful if you are announcing a major project or event. Keep in mind that reporters are inundated with information about potential stories. If you send them too much information, they may not have time to read it.

- Cover memo or press release with contact name and phone number
- Fact sheets on the issue
- · History of the issue
- · Quotes or comments by experts
- Selected press clippings
- City-by-city analysis (or countryby country)
- Speeches or statements on the issue

- Charts, visuals or photographs
- Background biography on spokesperson
- Copies of speeches
- Standard one-page description of your organisation

Using Social Media

With the growth of social media, people are increasingly being channelled to new websites. Facebook, Twitter and LinkedIn are important tools for getting your message across to a younger audience and to media, to say nothing of burgeoning networks like Google+ and Pinterest.

Each of these social media sites have huge followings which you can benefit from by initiating a social media campaigns to increase the digital reach of your patient advocacy initiatives. It may be that Facebook is not necessarily the right channel for your communication initiatives. So, the key issue is to decide which social media channel is the most appropriate to your target group and will help you reach your specific objectives. Every social network is different. Google+ will help you increase your rankings on the Google search engine whereas Pinterest is great for sharing photos with your followers. Twitter emphasizes text, whereas Pinterest focuses on pictures and Facebook is a cross of the two.

SOME TIPS FOR GETTING YOUR MESSAGE ACROSS

1. Communicate!

Do not post messages to your page but communicate with your followers. The goal is to build a community and establish connections between your association and your followers. For Facebook, you will need to reply to comments and tag fans in pictures and posts. For Twitter, you need to build your followers and then re-tweet them and start a conversation. LinkedIn is good for professional outreach you can join groups and post content to forums to achieve as great a reach as possible.

2. Be simple!

Edit your message. Use simple language making sure that your message will not be misinterpreted. Be clear about what you want to convey – what should be understood, what should be acted upon.

3. Develop a hook

Convey what is interesting and appealing about your message – why should your followers care.

4. Test your message

Send a test message to your colleagues before sending it out to a large community. Make sure the message is clear, that it can be remembered, followed up. Make it easy.

5. Use the right channel

Be different. If everyone is tweeting, consider a video message, or tell a story. Take a different slant. Use appropriate channels to convey your message to the right followers.

6. Reach out

Consider spreading your message via more than one social media channel. Tailor the content

however as each is different. Explain why it is important and what they need to do. Provide the content and the tools. Make it easy.

7. Ask For help

Engage your volunteers in the process and ask for their help. Shape your message for the key influencers. Some will not follow but it is all about numbers. Tell them why it is important and ask for specific actions – email or re-tweet the message etc.

8. Appeal to their emotions

It is not about your association's mission but about your followers' interests. Relate to their needs. Why should they care? Provide the hook. Explain the next step. Direct them to your website for more information. Do not copy what is on your website, be sure to tailor the message to your social media network and attract different groups to the social networks and to the website – they should not mirror each other

9. Appeal to action

Using short words and sentences, appeal to action. Make it urgent. What will happen if no action is taken, What are the key issues.

10. Keywords

Use key words. The words they will use to search for news. Use the key words in the headlines as well as the text. Appeal to their interests. Be short. Make one essential point, and explain it. Tailor to your audience.

Remember, it is not about you or your association and what you think you are saying. It is about your audience, what they understand and how they react!



About ENGAGe

What is ENGAGe?

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups is a network of European patient advocacy groups established by ESGO representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva and rare cancers).

Why is ENGAGe needed?

- There are wide variations in patient care across Europe. Patients are not adequately informed about gynaecological cancer and their management.
- Survivorship issues are not adequately addressed and psychosocial support in general is poor.

The ENGAGe objectives are to:

- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- To increase patient representation in ESGO activities by education on current research and health policy.
- To advocate patient care policies practices and access to appropriate care at both national and European levels.
- To educate patient groups, health professionals, the public and health decision makers.

Contact us:

ENGAGe

Email: esgo.engage@gmail.com Web: www. esgo.org/ENGAGe/Pages/Home.aspx