





Irish Society of Gynaecological Oncology Public and Patient Involvement Group (ISGOPPI)

Origins

The Irish Society of Gynaecological Oncology (ISGO) re-established in Dec 2015. The society is an all-Ireland venture encompassing all gynaecological cancers. Its members are lead clinicians, nurse specialists, scientists and allied health working in the area of Gynaecology Oncology in Ireland. They meet several times a year. The society will focus on the full continuum of cancer care; from prevention to diagnosis, treatment, survivorship and palliation.

What is PPI?

The society realised the importance of including the Patient and Public voice in the management of all aspects of Gynaecological Oncology. The term “public” refers to potential patients, significant others and people who use health and social care services as well as people from organisations that represent people who use these services. The Society would like that its PPI group would play a role in improving Patient Experiences and Clinical Research but not exclusively just these areas. Our hope is that by having a partnership with our patients, we can achieve more as a group and you have a better Patient Experience.

Commitment

The group aim to meet 3 times a year and correspondence is mainly through email. A number of our members are involved in national and international committees and further education around PPI.

ISGOPPI Co-founders

Yvonne O’Meara and Sharon O’Toole established and run the ISGOPPI. Yvonne is a Systemic Psychotherapist & Psycho-Social Oncologist. Yvonne has worked in the area of psycho social oncology and palliative care since 2004 in teaching hospitals in Ireland and in North America. She has recently taken up a post at the University College Dublin School of Medicine as Women’s Cancer Survivorship Research Coordinator based in the Mater hospital.

Sharon is a Senior Research Fellow in Trinity College Dublin working in the area of gynaecological cancer. Her research focuses on early diagnosis and better treatments. Sharon works closely with a number of ovarian cancer charities in Ireland and coordinates the national awareness events in Ireland for gynaecological cancer.

Where can I find out more?

More information please email: isgoppi@gmail.com



[@ISGOPPI](https://twitter.com/ISGOPPI) / Twitter



[ISGOPPI](https://www.facebook.com/ISGOPPI) | Facebook

Welcome to our Annual Newsletter,

2020 has been a strange and difficult year for everyone and we hope that you and your families have stayed safe and well. While the restrictions impacted on face-to-face meetings in 2020, we have tried to continue our work and move to online platforms. Many virtual events took place during the year and we hope you enjoy reading about these.

Despite the restrictions, the group has been very productive. Moving to virtual platforms brought some advantages also in terms of more people being able to attend events and not having to travel.

We thank you for your support and hope you continue working with us going forward to improve the experience for women and their families diagnosed with gynaecological cancers. Please feel free to pass on this newsletter to anyone who may be interested as we welcome new members.

Sharon and Yvonne.

Activities 2020

1. Education and Advocacy

One of our members Anne Nally-Keenan took part in an education series “Conversations that matter” looking at the impact of COVID-19.

Conversations that matter ...

As part of our suite of resources, the RCSI Institute of Leadership, in partnership with the HSE, is hosting a 30-minute webinar series weekly, entitled ‘**Conversations that matter ...**’.

These conversational webinars aim to create dialogue and honest exchange on the current issues faced by the system and those working in it. Healthcare professionals dealing with the challenges presented by COVID-19 will share their insights and learnings during this rapidly evolving crisis situation.

These webinars are free to attend and take place every Thursday at 6:30pm.

Please note: RCSI is also hosting a weekly webinar for surgical teams. [Learn more here.](#)

Upcoming webinars

- Thursday, 14 May 2020: Patient Perspective in COVID-19

Guest speakers

- **Dr Miriam Colleran** - Consultant in Palliative Medicine, St. Brigid's Hospice and Naas General Hospital
- **Dr John Fitzsimons** - Consultant Paediatrician, Temple Street, Clinical Director Quality Improvement
- **Marie Ennis O'Connor** - Keynote speaker and social media strategist in Ireland

- Anne also shared her story in the Irish Independent to raise awareness of cervical cancer and its aftermath.

[‘I survived cervical cancer - but I live with its devastating aftermath’ - Independent.ie](#)



European Network of Gynecological Cancer Advocacy Groups (Engage)

ISGOPPI is a member of the Engage network which is part of the European Society of Gynaecological Oncology (ESGO). The Engage network has a number of ongoing projects and committees that our members now sit on. ISGOPPI has a representative on the clinical trials project. The Clinical Trial project headed by Birthe Lemley and in cooperation with ENGOT is ongoing, with some delays due to the pandemic. A study book on clinical trials is being prepared to help patients understand more about clinical trials and how they work.

Engage has also established cancer specific committees and ISGOPPI members sit on some of these.

Engage Survey

Many of the ISGOPPI members took part in a survey run by Engage to assess the impact of COVID on gynaecological cancer patients across European countries. The results were recently published and acknowledge ISGOPPI for their contribution.

Received: 21 September 2020 | Revised: 14 October 2020 | Accepted: 23 October 2020

DOI: 10.1002/cam4.3605

ORIGINAL RESEARCH

Cancer Medicine  WILEY

Perspectives, fears and expectations of patients with gynaecological cancers during the COVID-19 pandemic: A Pan-European study of the European Network of Gynaecological Cancer Advocacy Groups (ENGAGE)

[Click here for full details of paper.](#)

2. Awareness Event: World Ovarian Cancer Day 8th May 2020

A number of National organisations came together to highlight ovarian cancer symptoms for world ovarian cancer day. The groups involved included; Breakthrough Cancer Research, Cancer Trials Ireland, East Galway and Midlands Cancer Support Centre, Emer Casey Foundation, Irish Cancer Society, Irish Society of Gynaecological Oncology, Karen Fenton Ovarian Cancer Fund, Lynch Syndrome Ireland, Marie Keating Foundation, National Cancer Control Programme, OvaCare, SOCK, St. James' Hospital Foundation (GynaeCancerCare) and Trinity College Dublin.



In the past we held a number of information sessions around the country but this year was different due to COVID, so all events were held virtually.

Breakthrough Cancer Research organised a number of online seminars through their social media channels. Links are available by clicking below;

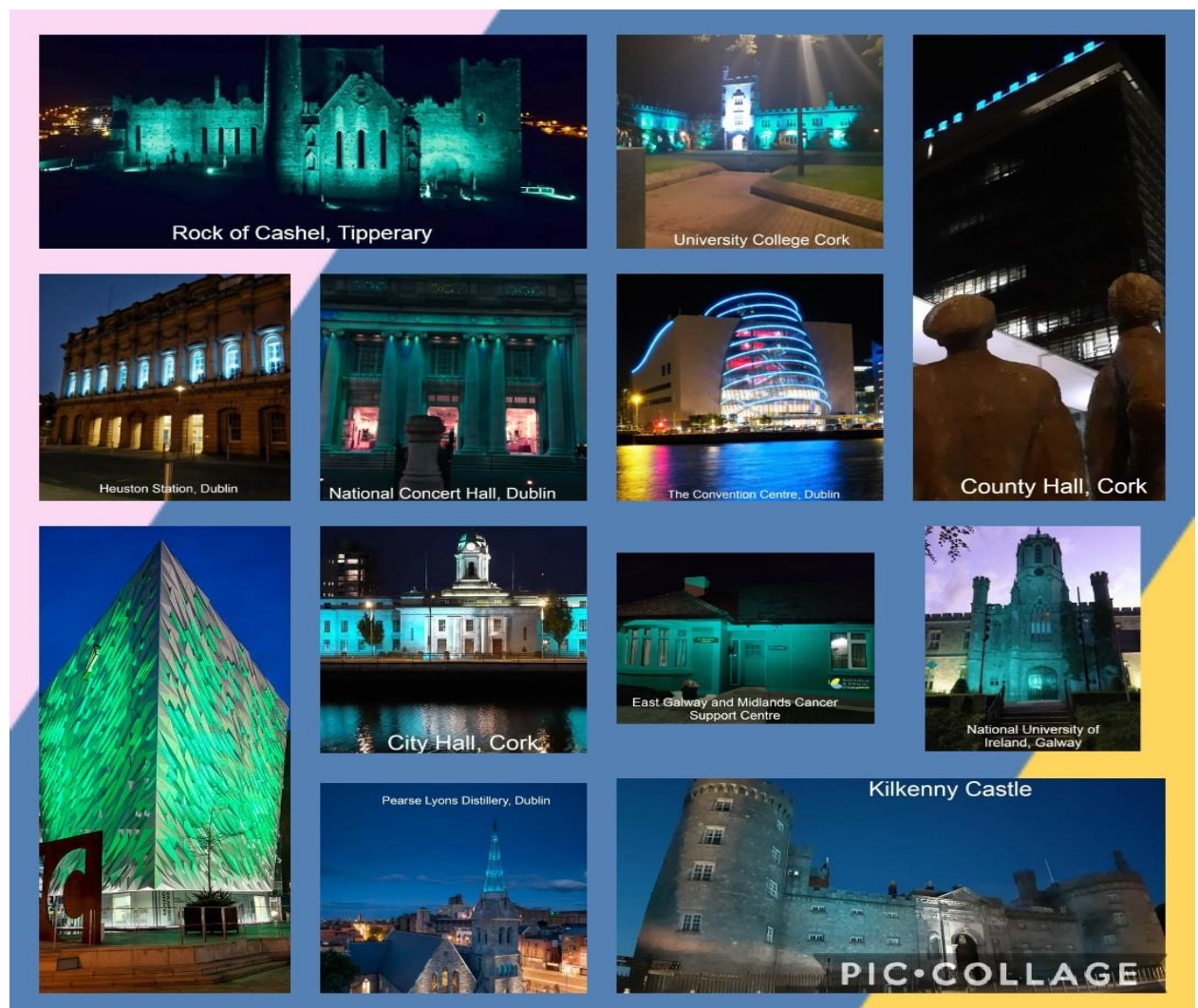
- Dearbhaile Collins [World Ovarian Cancer Day 2020 - An Oncologist's Viewpoint \(19k views\)](#)
- [Jennifer Quinn](#) Overcoming Ovarian Cancer Recurrence and Drug Resistance - Emerging Research (4.3k views)

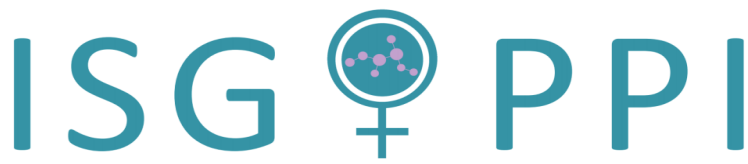
Marie Keating organised the first virtual BRCA seminar

- [First ever virtual BRCA seminar in Ireland - Marie Keating Foundation \(click on link\)](#)
- Ovacare hosted its first virtual coffee and chat which proved very successful and continued monthly for the rest of the year.

Light Up in Teal

To mark World Ovarian Cancer Day, the following buildings agreed to 'Light Up in Teal', the colour associated all over the world with the fight against ovarian cancer – City and County Halls, Cork; Convention Centre, Dublin; East Galway and Midlands Cancer Support Centre, Ballinasloe, Co. Galway; Heuston Station, Dublin; Kilkenny Castle; National Concert Hall, Dublin; National University of Ireland, Galway; Pearse Lyons Distillery, Dublin; Rock of Cashel, Tipperary; Titanic, Belfast; University College Cork.





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Media outputs

TV Advert used each year created by OvaCare:-

<https://www.youtube.com/watch?v=TFO-xpvnQNw>

[Irish GP trying for baby had life saved when doctor found ovarian cancer - Irish Mirror Online](#)



Twitter

[The Emer Casey Fndtn on Twitter: "In Ireland we are lucky to work with incredible ovarian cancer researchers, healthcare professionals, advocates, patients and their families ... we are honoured to mark World Ovarian Cancer Day with them today and to amplify their #PowerfulVoices #WOCD2020 https://t.co/KelD8TAymQ" / Twitter](#)

3. Awareness Event: World Gynaecological Oncology Day 20th Sept 2020

A number of national organisations, patient advocacy groups and researchers joined in the global Gynaecological Oncology “GO” Day. Raising our voices in solidarity in Ireland are; Breakthrough Cancer Research, Cancer Trials Ireland, CERVIVA, East Galway and Midlands Cancer Support Centre, Emer Casey Foundation, Irish Cancer Society, Irish Society of Gynaecological Oncology, Karen Fenton Ovarian Cancer Fund, Lynch Syndrome Ireland, Marie Keating Foundation, National Cancer Control Programme, National Immunisation Office, OvaCare, Sláinte an Chláir, SOCK, St. James’s Hospital Foundation (GynaeCancerCare), Trinity College Dublin and 221+ CervicalCheck Patient Support Group.



Light Up in Purple

To mark World Gynaecologic Oncology Day, the following buildings agreed to ‘Light Up in Purple’, the colour associated all over the world with the fight against Gynaecological cancers – City Hall, Cork; The Convention Centre, Dublin; East Galway and Midlands Cancer Support Centre, Ballinasloe, Co. Galway; The Mansion House, Dublin; Millmount, Drogheda, Co. Louth; The National Concert Hall, Dublin; National University of Ireland, Galway; Pearse Lyons Distillery, Dublin; Rock of Cashel, Tipperary; Titanic Belfast and University College Cork.

Worldgoday 2020



PIC•COLLAGE

- Awareness event, Circle of Friends, Tipperary.



- Online Seminars

[World GO Day - Medical Oncologist Dr. Dearbhaile Collins talk - A Focus on Gynaecological Cancers](#)

- Media Outputs

[Drogheda Life | Best News & Advertising | Latest News | Millmount to go purple for World Gynaecologic Cancer Day](#)

- Mummy pages <https://www.mummypages.ie/irish-landmarks-will-turn-purple-for-world-gynaecologic-oncology-day>

- Social Media Awareness (poster from Sláinte an Chláir)

GYNECOLOGIC CANCER SYMPTOMS	Cervical Cancer	Ovarian Cancer	Uterine Cancer	Vaginal Cancer	Vulvar Cancer
Abnormal vaginal bleeding or discharge					
Feeling full too quickly or difficulty eating					
Pelvic pain or pressure					
More frequent or urgent need to urinate and/or constipation					
Bloating					
Abdominal or back pain					
Itching, burning, pain, or tenderness of the vulva					
Changes in vulva color or skin, such as a rash, sores, or warts					

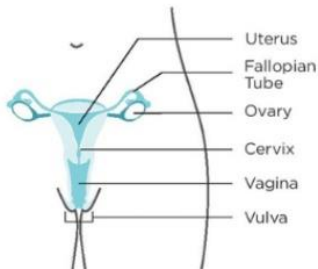
World GO Day


20th September 2020

World GO Day

Gynecologic cancers have warning signs. See your doctor if you have any of these symptoms for two weeks or longer. And if you have vaginal bleeding that's not normal for you, see your doctor right away.

It may be nothing to worry about, but find out for sure. Get the *Inside Knowledge* about gynecologic cancer!

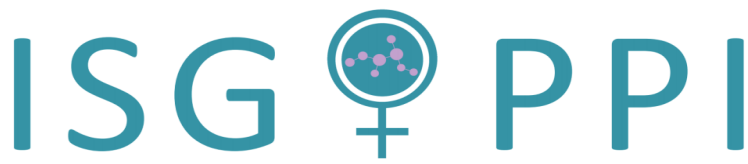




SLÁINTE AN CHLÁIR, CLARE CANCER SUPPORT CENTRE 087 6912396
WWW.CLARECANCERSUPPORT.COM

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20th September 2020



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World GO Day Video

ISGOPPI was delighted to take part in World GO Day, this video link below was created by the organisers and features some of the Irish organisations that submitted videos for the day.

[ENGAGe - GO Day Celebration 2020 - YouTube](#)



World GO Day
September 2020



CERTIFICATE OF APPRECIATION

Proudly presented to

Irish Society of Gynaecological
Oncology Public and Patient Involvement
(ISGOPPI)

for their participation

WORLD GYNECOLOGIC ONCOLOGY DAY

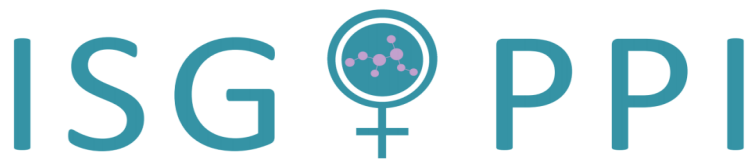
20 SEPTEMBER 2020

#GoForPurple

#WorldGoDay

worldoday.org





**Irish Society of Gynaecological Oncology Public
and Patient Involvement Group**

4. ISGOPPI Information Leaflet

Together with our members we have designed the leaflet below, thank you for your contributions.



**The Irish Society of
Gynaecological Oncology
Public and Patient Involvement
Group (ISGOPPI) would like to
invite you to become part of a
dynamic group of individuals
who have been directly
impacted by a gynaecological
cancer or have a special interest
within this area of health care.**

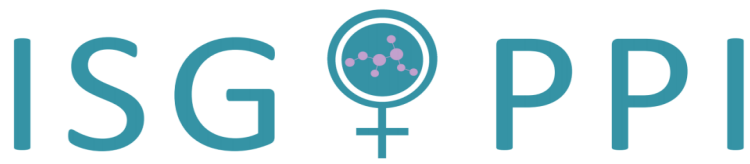
The Irish Society of Gynaecological Oncology (ISGO), which was re-established in December 2015, is an all-Ireland venture encompassing all gynaecological cancers.

Members include lead clinicians, nurse specialists, scientists and allied health professionals working in the area of Gynaecological Oncology in Ireland.

The society meets several times a year focusing on the full continuum of cancer care; from prevention to diagnosis, treatment, living with and beyond cancer and palliation.

"Being part of the ISGOPPI has been fulfilling personally, it is rewarding to utilise my experience as a patient in a positive way by influencing research...."





**Irish Society of Gynaecological Oncology Public
and Patient Involvement Group**

What is PPI?

The society realised the importance of including the Patient and Public voice in the management of all aspects of Gynaecological Oncology. The term “public” refers to all patients and persons who use health and social care services, this includes members from organisations that represent people who use these services.

The PPI group plays a vital role in improving patient experience and clinical research but not exclusively to just these areas. Our aim is to have a strong partnership with our patients and therefore achieve more as a group and encourage better patient experience.

Achievements

- Representation on The National Guidelines for Ovarian Cancer.
- PPI led research on Doctor Patient Communication published in the Irish Medical Journal Summer 2019.
- Members have represented the ISGOPPI at National and International meetings.
- Members of the European Network of Gynaecological Cancer Patient Advocacy Groups (ENGAGe) and World Gynaecological Oncology (GO) Day working group.
- Feedback to research groups on design of studies, content of patient information leaflets and circulation of findings.
- Participating in “Life Beyond Cancer” focus groups.
- Influencing change in programmes such as the Irish Cancer Society’s Women’s Health Initiative.

Commitment

The society aims to meet twice a year, the location rotates around Ireland and often coincides with an ISGO scientific meeting.

The society corresponds through email outside of these meetings. You can choose to partake in projects throughout the year if you wish.

For further information:

E: isgoppi@gmail.com

W: www.isgo.ie



5. National and International Meetings

Due to the COVID restrictions many meetings were held virtually. This did give an opportunity for people to attend and in particular to the European meetings. Members of ISGOPPI attended the;

- Patient Voice in Cancer Research on 25th Feb 2020.
- ESGO Engage patient advocacy week.
- Irish cancer society “Living well with and beyond cancer” virtual conference Tuesday, 29th September and Wednesday, 30th September 2020 (recordings available online).



The Patient Voice
In Cancer Research



NCRI
National Cancer
Research Institute
Partners in cancer research



ENGAGE
European Network of Gynaecological
Cancer Advocacy Groups



VIRTUAL PATIENT ADVOCACY WEEK
30/11 - 5/12 2020

The Patient Voice in Cancer Research in conjunction with the **National Cancer Research Institute (UK)** presents:

Dragons' Den – involving patients and carers in cancer research

Tuesday, 25th February 2020
4pm-7pm,
Galway Bay Hotel, Salthill

Free registration via Eventbrite.
Search for The Patient Voice in Cancer Research
Contact: patientvoicecancer@ucd.ie
or phone: (01) 716 6809

The Patient Voice in Cancer Research is supported by Irish Cancer Society research grant PVCRI9MCC

In partnership with:





PROGRAMME

Monday 30/11	
① 10 a.m. Patient doctor communication - importance of patient advocacy groups Ico Toth, Sara Nassier (Storytelling on FB page)	② 2 p.m. What should I ask when I find out I have a cancer Kim Hulcher (Best practice sharing on FB group)
Tuesday 1/12	
① 10 a.m. Rare cancer Eva-Marie Stromholm (Storytelling on FB page)	② 2 p.m. GO Day all over the world Petra Adámková (Best practice sharing on FB group)
Wednesday 2/12	
① 10 a.m. Endometrial cancer Maaike (Olif) (Storytelling on FB page)	② 2 p.m. „How can I live now” Initiative from Ukraine Natalya Khandobina (Best practice sharing on FB)
Thursday 3/12	
① 10 a.m. Cervical cancer Anne De Middelaeler (Storytelling on FB page)	⑤ 6-6:30 p.m. PARP-inhibitors: patients ask and doctors answer Jonathan Ledermann (Webinar)
② 2 p.m. Sweden free of cervical cancers in 5 years Barbro Sjölander (Best practice sharing on FB group)	⑥ 6:30-7:00 p.m. Patient Associations' role during the Covid-19 pandemic Ico Toth, Kim Hulcher, Murat Gultekin (Webinar)
③ 5-5:15 p.m. PAW Welcome word Philippe Morice, Ico Toth, Murat Gultekin (Webinar)	⑦ 7:10-7:40 p.m. Cervical cancer - the preventable disease - Today's tools and possibilities, challenges and opportunities for Eastern Europe Murat Gultekin, Princess Nothembha Simelala (WHO) (Webinar)
④ 5:15-5:45 p.m. Endometrial Cancer: early or late, advancements in tools and possibilities Philippe Morice (Webinar)	
Friday 4/12	
① 10 a.m. Ovarian cancer Malgorzata Kretowska (Storytelling on FB page)	④ 5:15-5:45 p.m. Clinical Trials Project: How far are we? Birthe Lemley, Jalid Sehouli (Webinar)
② 2 p.m. Rehabilitation/ quality of life Ico Toth (Best practice sharing on FB group)	⑤ 5:45-6:15 p.m. We rarely hear about rares Nicholas Reed (Webinar)
③ 4-5 p.m. Palliative care: mapping the situation in diverse countries Karina Dahl Steffensen, Annette Hasenburger, Karim Zalewski, Maja Pakiz (Virtual classroom)	⑥ 6:30-7 p.m. Is the ovarian cancer really an ovarian cancer? Ranjit Manchanda (Webinar)
Saturday 5/12	
① 10-10:45 Integrative medicine Jeanette Kertevig (Webinar)	② 10:45-12:00 General Assembly

SOCIAL PROGRAMME
1:00-3:00 p.m. Emotional photography • 3:15-3:45 p.m. Line dance • 4:00-5:00 p.m. Yoga class
5:30-6:30 p.m. Cooking class • 6:30-7:30 p.m. Final toast









Home > Living Well With and Beyond Cancer

LIVING WELL WITH AND BEYOND CANCER CONFERENCE 2020

ONLINE EVENT

Tuesday 29th September & Wednesday 30th September

Attendance is free of charge

Register at www.cancer.ie/LivingWell



6. Women's Health Initiative

The Irish Cancer Society in 2020 established the Women's Health Initiative (WHI). Its aim is to improve health and wellbeing for women living with and beyond cancer through the establishment of pilot clinics based in Cork and Dublin. The clinics will involve initial groups of selected participants. As you maybe aware Sharon and I both work within the area of women's health. I was successful in a recent interview and was appointed Women's Cancer Survivorship Research Coordinator. This post is part of the WHI appointed by UCD School of Medicine. I find myself in an extremely fortunate position where the research that we are conducting has strong ISGOPPI input from the very start. I was appointed in October 2020 and since this time we have formed two working groups compiling of 5 members of the ISGOPPI in each group, conducted three workshops attached to two projects and have had ISGOPPI input on all other projects attached to the Dublin based WHI. I would like to take this opportunity to say a massive thank you for all your input so far, we listen to what you say and we are acting on it. I look forward to working with you in 2021.

Two specific projects that the ISGOPPI have been involved in are below.

The Diagnosis Delivery project

Survivorship begins on diagnosis, the delivery and information shared of a new diagnosis of cancer is particularly important to patients. Managed correctly it can have a positive impact on their ability to cope with what lies ahead. When this phase is managed well it sets the tone for future care and can build up trust between patient and care provider. Currently there is limited structure to support staff during this phase of a diagnosis. The Diagnosis Delivery (DD) project will aim to support staff and women in a more organised manner, so that diagnosis is delivered in a clear and compassionate manner. Particular focus will be placed on the act of delivering a diagnosis to a patient; when is it performed in their disease journey, how is the information delivered, what information is shared at this time and how is that information retained by the patient and/or their significant others.

Virtual Passport

Our objective is to develop a personalised treatment summary and passport for women with individualised information for each patient based on their disease site, stage and treatment modalities received using a virtual platform. Once developed this platform will be scalable to many other cancer types. Phase one of this project will focus on cervical cancer. Our long-term goal is to create an interactive mobile enabled webpage where any woman impacted by gynaecological cancer and breast cancer can access and enter their personalised medical history and treatment plan. Depending on their symptoms an individual virtual passport outlining resource and solutions both local and national will be made available to the individual women. This will include a range of resources within their area/region, podcasts/educational videos and peer support. The main aim is to empower those women with information, information that they can access in their own time and that is relevant to them. This platform will also offer support to the wider family system.

7. Laura Brennan Award

The Irish Society of Gynaecological Oncology (ISGO) put out a call for nominations for the Laura Brennan Award. Laura had received the inaugural award in Belfast in 2018 for her endless campaign for the HPV vaccine. Joan Moore was a worthy recipient of the award in 2019. With Laura, it was decided that the Laura Brennan Award would be presented on an annual basis by the ISGO to a patient or member of the public as a recognition of outstanding achievement in the areas of gynecological oncology patient advocacy and or patient and public involvement in research.

ISGO received a number of nominations and with the ISGO committee, a representative from our PPI group and Laura's parents Bernie and Larry, it was decided that Jacqueline Daly (member of ISGOPPI) was a worthy recipient for this year's award. A presentation will be organised when restrictions allow.

Jacqueline co-founded East Galway & Midlands Cancer Support in 2012 and is now Director of Services, as well as a patient advocate and campaigner, bringing awareness to local and national government agencies. She is an active member of the ISGOPPI and patient representative on the board of the Society of Sexual Medicine Ireland. She is also secretary of the board of the European Cancer Patients Coalition (ECPC). She has contributed to the ECPC Publication 'Living Well During Cancer Treatment', wrote the Structured Education Programme (STEP) to support men with Prostate Cancer and participated in ESMO Rare Cancer Patient Advocate Training in Milan 2018 and spoke at the ESMO Conference in Munich 2018. On top of this she is a complimentary therapist in Bio Energy, Healing Touch, Indian Head Massage, Reiki, Rahanni and a developer and presenter of community outreach programmes, including facilitator for Survive and Thrive Self-Management programme for Cancer Survivors run by the National Cancer Control Programme in Ireland. She is a facilitator of the Climb program for children between age 5 – 12.

Both Jacqueline and her husband Mike had cancer and know both as carers and as patients how important proper support and information is. The Cancer Patients voice must be heard. Jacqueline is a worthy recipient of the 2020 Laura Brennan Award.



PLANNED ACTIVITIES 2021

Virtual workshops (email notification)

May 8th 2021 World Ovarian Cancer Day

September 20th 2021 World Gynaecological Cancer Day

Autumn 2021 ISGO Annual Meeting (Date to be confirmed)

Acknowledgment

In 2020 we had a number of members that died as a result of gynaecological malignancy. In their death, we lost some fantastic and amazing patient advocates who really wanted to make a difference in gynaecological oncology. We fondly remember them and their contributions. On behalf of ISGOPPI we would like to thank them for their contribution and for trying to make a difference for all women with gynaecological cancer. We hope their contribution will inspire others. We offer our sincere condolences to their families. Ar dheis De go raibh a n-anamacha.