

Patient Advocate in Cancer Research

Award 2024

Guidelines

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Patient Advocate in Cancer Research Award 2024

Your Guidelines

1. What's this about?

1.1. Summary

An advocate is someone who supports or defends a cause. A patient advocate for cancer research is a voice for cancer patients.

This award is to directly fund a patient advocate to upskill themselves in areas of cancer research, PPI, and cancer research advocacy. You can be a patient advocate for cancer research, a PPI contributor, or both, to apply for this award. You may also have no experience yet and want to apply to start out your cancer research advocacy/PPI journey. This award is for anyone, regardless of experience, who wishes to upskill in this space.

Patient Advocate

Someone who is building their knowledge or meeting new people in the cancer space

Patient Involvement (PPI) Contributor

Someone who is partnering with cancer researchers in research projects

These two terms are closely linked and you might identify as both a Patient Advocate and a PPI contributor.

The Irish Cancer Society knows how important cancer research advocates are. Our advocates are driven by their own cancer experience, they want to contribute to the improvement of treatments and understanding for patients coming after them.

We also know that in cancer research advocacy, knowledge and making connections is key. For example, by going to cancer research events, going to training or attending workshop. However, it can be difficult to fund this yourself, especially if on a reduced income. We know the potential expense involved can stop people from taking part and becoming cancer research advocates.

As part of our commitment to developing a community of cancer research advocates, we are advertising the Patient Advocate in Cancer Research Award. The award will give funding to **support patient advocates in cancer research**. This funding can be used in 2025.

Aside from this award, we do have the PPI awards where cancer researchers partner with PPI contributors in their research projects. If you would like more information here is the <u>link</u> to the previous award. We are hoping to launch the next call in 2025.

Please read this entire document carefully before completing your application. If you are interested but have some questions, please feel free to get in touch by email grants@irishcancer or on (0)1 968 3723. Please note that the term "event" means any activity/ training/ conference and so on that you would like to attend.

1.2. Timeline

| What's happening? | By when? |
|-------------------------------------|---|
| Accepting applications | Opens Thursday 29 th August 2024 |
| Deadline for receiving applications | Closes Thursday 31 st October 2024 |
| When decisions are made | November |
| Awardees announced | End of November |

Please note: The above dates may change, by decision of the Irish Cancer Society.

1.3. Purpose and Objectives

The purpose of this award is to fund **new or experienced patient advocates** for **cancer research**.

You should be able to show how getting funding will help your own development, enhance your skills through training programmes, and support you in engaging in cancer research PPI opportunities. The ultimate goal, is that you will have a positive impact on the cancer research PPI community in Ireland.

You are not expected or need to be a speaker at these events. You can be an observer. These events can be used to learn how patient advocates can get involved in research or used as a networking opportunity.

The following are some examples of patient advocacy and PPI events that past awardees used their Patient Advocacy Award to attend. These events can be in Ireland or can be international.

- Relevant cancer symposiums such as the <u>International Lobular Breast Cancer</u> (ILC) <u>symposium</u>
- PPI training/ summer school such as <u>The Irish Platform for Patient</u>
 Organisations, Science & Industry (IPPOSI)
- Patient advocacy track on <u>European Society for Medical Oncology (ESMO)</u>
- Other types of patient events/ workshops/conferences such as those listed in:
- PPI Ignite Network
- Irish Association for Cancer Research (IACR)
- European Patients' Academy of Therapeutic Innovation (EUPATI)
- CREATIVE FACILITATION Training for Transformation
- Childhood Cancer Europe Conference 2024
- PanCare Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer
- WECAN Academy 2024: Empowering Cancer Patient Advocates in Barcelona -European Patient Advocacy Institute
- WECAN Advocate European Cancer Patient Advocacy Network
- Patient Partnership MASCC
- European Cancer Congress Organisation
- Cancer Patients Europe Working to improve the lives of the cancer community
- Get Involved ECPC European Cancer Patient Coalition
- European Patient Forum

We are not connected to any of the above, these are provided only as examples, and you can apply to other events instead. It is best to do your research on events you would be interested in. Just make sure you explain why this event would be good for you.

Funding is available to cover the costs associated with advocating for cancer research. This may include:

- Registration costs for a conference, workshop, course or training activity (online, hybrid or in-person)
- Travel costs
- Childcare costs to cover time required for PPI activities
- Loss of earnings due to time commitments required to be a PPI contributor
- Accommodation costs
- Meals
- Materials needed for PPI activities (for example, Microsoft office subscription, a webcam etc.)

This is a suggested list; other costs can be covered if you tell us why they are needed. What funding will be covered is decided by the Irish Cancer Society.

This award is only meant to fund you going to events that will benefit your own development. It is not meant to fund a PPI project you are already working on. For example, you cannot use this award to work on a cancer researcher's project or on behalf of a cancer researcher.

Since COVID-19, some events or activities may be online. For in-person events, please make sure you follow the public health guidelines in place at that time.

Funding for equipment (for example, a headset) will be decided by the Irish Cancer Society. If this is the case, we will need a good reason why the item is needed and will need a quotation including item description and costs.

For more detailed information on costs that may be covered please see section 2.2

1.4. Funding and how long does this award cover costs for?

There are a **minimum of five** awards available, where each award is worth **up to a maximum of €1,000**. Funding is to cover registration, travel, accommodation, childcare, loss of earnings, materials and meal costs. The event(s) must happen between January 2025 and January 2026.

Please see **section 2.2** for more details on costs that the award will cover.

Once explained in the application, you can use the funding for more than one event if needed. For example, going to online events may be cheaper than going to an in-person event. This means you can potentially go to both events. However, the **maximum** funding amount per applicant must be no more than €1,000.

It's very important to explain the benefits of attending each event/activity and the reasoning for the costs. You must also include a **rough** breakdown of all costs in your budget. You will need to show how you calculated the amounts within each category

(for example, a breakdown of costs for meals, for event registration, and so on). It does not need to be exact, but this is just to give us an idea of where your budget is going. We are happy to chat about this over the phone or email if you need more help.

2. Can I apply?

2.1. Who can apply for this award?

This award is open to all cancer research advocates (new and experienced).

The award is for people who would usually not have access to research grant awards or travel awards. Applications will **not be accepted from professionals employed within the cancer space**. For example, you cannot apply if you are a cancer researcher, allied health professional, oncologist and so on.

You do **not** need to have any experience in cancer research advocacy to apply. Applications from cancer research advocates who are **new in this area OR who have experience** are welcomed. Advocates who have won this award in 2022 may still apply, but preference for this award will be given to a **first-timer**.

You do not need to be a member of the Irish Cancer Society PPI Panel to apply for this award. This call is open to all cancer research advocates in Ireland.

| Can I apply? | |
|--|----------|
| I have never done cancer research advocacy before | ✓ |
| I am a current cancer research advocate | ✓ |
| I am part of the Irish Cancer Society PPI Panel | ✓ |
| I am not part of the Irish Cancer Society PPI Panel | ✓ |
| I have won this award before | ✓ |
| I am on the PPI Panel of another organisation | √ |
| I am already funded to go to the event I had in mind | * |
| I am a professional working in the cancer space | * |

2.2. What costs will be covered?

What do I need to know about costs?

Events, Training and Conferences

You can apply for funding for cancer research events (attend meetings, conferences, workshops, or training events... and so on) which will support your cancer research advocacy or PPI activities directly. Please get in touch with grants@irishcancer.ie or (01) 968 3723 if you have any questions.

Examples of event-related costs:

- Conference registration fees
- Workshop registration fees
- Training course fees

Travel

- We encourage public transport when possible and when this is the cheapest option. Public transport should be booked in advance and should be standard class or economy class only.
 - We know for practical or health reasons, public transport may not always be possible. If this is the case, just let us know in your application (you do not need to give medical details)
- Taxis may be used when there is no other choice. If possible, taxis should be shared and should result in no extra fees. For example, waiting time charges or tips.
- If the event(s) is in Ireland but you can't get there by public transport, you may use your own car to travel to and from the event. A standard motor travel rate of €0.44 per kilometre is allowed. The motor travel rate paid is meant to cover all expenses of running the car. For example, insurance, tax, petrol and so on.

Accommodation

• The cost of accommodation should be reasonable and only booked for however long the event is. However, if the event starts in the morning and you need time to travel to that city, you may book a room for the night before the event. You should book accommodation that is a 4-star rating or below. For national and international accommodation, rates will vary depending on the city and country, so it is hard to give a guiding rate. However, you should look for accommodation that is reasonable and roughly costs the same as the average daily hotel rate there. Please get in touch if you have any issues with accommodation costs. If

- you need someone to come with you (for example, a carer) please include this in your budget.
- Facilities and services in the hotel, which you will need to pay extra for, are not allowed. For example, wi-fi costs, breakfast (if not included in the room price and is over €10), room service, newspapers and so on.

Alcohol

 It is the Irish Cancer Society's policy not to fund alcohol or any form of entertainment.

Meals

- You can spend €10 for breakfast, €12 for lunch and €25 for dinner per person.
- An added tip or 'discretionary service charge' of up to 15% on bills is reasonable in countries where such charges are customary.

Childcare Costs

 Where reasonable, we will cover necessary childcare costs needed for you to attend a cancer research-specific event or activity. A standard rate of €60-70 per day or €10 per hour is allowed where this is necessary.

Carer Costs

• You may be a carer and need a replacement carer to allow you to go to events or activities. You should include this in your budget. We understand that you may have your own arrangements and costs can vary. If you are budgeting for carer costs, please reach out to us at grants@irishcancer.ie or on (0)1 968 3723.

Loss of Earnings

• Sometimes, you may not get compensation for your advocacy work. For example, taking time off work to participate in a patient review panel. If you are taking unpaid leave to go to the PPI activity, and if you are not already receiving funding from other sources, where reasonable, we may pay you to cover the loss of earnings. This is a standard rate of €17.50 per hour, €70 for a half day or €140 for a full day. Please note, loss of earnings will be paid after the event has taken place.

In some cases, receiving payment for cancer research advocacy events may affect payments for those who are receiving social welfare. **It is up to you to**

make sure that you are following all social welfare requirements and the requirements of your employers.

Materials and Administration Fees

 Sometimes, you may not have the materials needed to attend events or take on PPI activities. Where reasonable, we may cover the costs of materials and supplies needed for you to go to these events or activities. These items may include telephone costs, postage, stationery, subscription to software or journals, materials that help accessibility, equipment such as a webcam or keyboard and so on.

Please note: After the event(s), you must send a description of award income and expenses with all original receipts included. It's important to do so because if you do not provide receipts, or do not follow our budget guidelines, you will need to give back the funding (in full) to us. If you spend less than your budget, you must also give back the unspent amount to us.

We will only fund items and reimburse costs that have not been funded by any other source.

3. How do I apply?

Before applying, you should read this document carefully and contact grants@irishcancer.ie or call (01) 968 3723 if you need any help. We are happy to schedule a phone call to guide you through the process too.

3.1. How to Apply

We listened to previous feedback, and we have made applying for this award easier:

- You can send an email to <u>grants@irishcancer.ie</u> letting us know that you're interested. Please include your full name and contact number. If you'd rather phone us and let us know, call (0)1 968 3723.
- Please see **Section 4. 'What's in the application?'** for more information and read the entire section before writing your application.
- Please use the 'Application Form' Word Document and email this to grants@irishcancer.ie. You are free to use as much space as needed, provided it is within the word count (if applicable). If you would like a printed application form where you can handwrite your application, please do contact us on grants@irishcancer.ie or (01) 968 3723 – you can post your application to the address in Section 7.

4. What's in the application?

If you are applying with a Word Document, we recommend you saving your progress regularly by clicking 'Save'.

Please make sure all application sections are included, as unfinished applications could slow the process.

There are five sections that should be included in the application form:

- Applicant Details
- Event Details
- Have you applied for funding from any other organisations to attend the initiatives?
- · Benefits of Attending
- Estimated Budget. A rough breakdown of the needed budget is enough. If you
 are successful with this award, then we can happily work with you to finalise
 your budget

5. How does the Society decide?

Our Review Panel will decide who will get the awards. Your application will be read through and the applications that'd win will seem to be the best use of money, are achievable, have a reasonable budget and will have the biggest impact.

We will let you know by email or by phone if you were successful.

We will make sure that the people on the review panel who choose the successful applicant do not have any conflicts of interest.

6. What happens if I win this award?

Once you have accepted the funding, we will provide a welcome pack detailing all information you may need throughout your award. If you need help with registering for certain events, let us know.

After you have finished up your events, within 30 days you will need to:

- Post or email a report covering the event. A report template will be sent to you with your welcome pack, before the event(s) take place.
- Post or email the details of what money you spent by completing a financial report. A report template will be sent to you with your welcome pack, before the event(s) take place.

Attach original receipts for all expenses (please make sure you include all receipts which show how much you spent on each item).

This is to make sure that the funding was spent in the way that was described in the approved application, and to hear about how this benefitted you as a patient advocate.

We will support you throughout the award and in preparing these reports.

7. How do I get in touch?

If you need help or have any questions about the application or award, please contact the Irish Cancer Society Research Department:

Email: grants@irishcancer.ie or phone: (0)1 968 3723

Address: Research Department,

43-45 Northumberland Road,

Dublin 4,

D04 VX65