Role profile

Patient representatives for children and young people’s cancers

**Type of opportunity**
Patient representatives

**Time commitment**
Up to 2 meetings (London) and 2 days of home-based work per year

**Payment and expenses**
Travel expenses and £100 per meeting for your time and contributions

**SUMMARY OF THE OPPORTUNITY**

Cancer Research UK have made a long-term commitment to children’s and young people’s cancer research. We’re looking for patient and parent representatives affected by children and young people’s cancer to join one of two steering groups to shape and influence our work in this area.

These groups are currently made up of clinical and scientific experts in paediatric cancer research. Last year we asked people affected by children’s and young people’s cancers how best to include their input into our discussions. Their feedback highlighted the importance to involve cancer patients and their families in those meetings, as important decisions are being made.

**Opportunity 1:** Cancer Research UK (CRUK) Children and Young People Steering Group  
**Opportunity 2:** Experimental Cancer Medicines Centre (ECMC) Paediatric Strategy Group.

**COVID-19 update:** As a result of the COVID-19 (coronavirus) outbreak, and advice from the Government, all our face to face involvement activity has been put on hold and many meetings have now been either postponed or will be held as teleconferences. Please note that more meetings may be cancelled and rescheduled to later dates. We are keeping people affected by cancer at the heart of what we do, so your involvement is still so important. In light of this, we want to continue with recruiting for patient representatives and involve you remotely to start with until we’re able to bring you in for face-to-face meetings again in future. We will continue to communicate with you throughout this period of uncertainty and if you have any questions, please do not hesitate to contact us at involvement@cancer.org.uk or call us on 0203 469 8777.
1. CRUK for Children and Young People's Steering Group
The Cancer Research UK for Children & Young People Steering Group is a new initiative bringing together researchers and clinicians representing a spectrum of scientific disciplines and expertise to identify the key strategic priorities which, if achieved, will improve survival and long-term outcomes for children and young people with cancer. They do not review grant applications or make decisions on research funding. We want this multi-disciplinary group to work together to proactively identify and recommend new opportunities and strategic initiatives where support could make a significant impact to people aged 0-24 with cancer. Members will also work to embed a focus on children’s and young people’s cancer research in the UK and international research communities, including those not traditionally associated with research into these types of cancer (e.g. research that looks into how the body develops or how the immune system works).

Length of role: This is a pilot project established in 2020 and membership will be reviewed after the first year (about two meetings).

2. Experimental Cancer Medicine Centres (ECMC) Paediatric Strategy Group
The Experimental Cancer Medicines Centres (ECMC) Paediatric Network is funded by Cancer Research UK, the National Institute of Health Research and the Chief Scientific Office. It's made of 11 centres and brings together doctors and scientists to improve the experimental clinical trials landscape for children. The ECMC Paediatric Network provides the infrastructure in the UK to deliver early phase clinical trials for children and young people.

The ECMC Paediatric Strategy Group (PSG) was established in 2017 and includes doctors from each of the 11 centres in the network, scientific experts and the Network Manager. The aim of the group is to develop strategic plans and support activities for the ECMC network which hope to improve the access for children and young people to experimental medicine and new treatments. The PSG meets twice a year to discuss how to improve collaboration across the network and tackle shared challenges faced in accessing experimental cancer medicine for children. They do not review grant applications or make decisions on research funding. You can read more about the network on our website: http://www.ecmcnetwork.org.uk/paediatric-network

Length of role: The ECMC patient representative role will be a two-year pilot, which will include four meetings between now and February 2022.

THE FOLLOWING INFORMATION IS APPLICABLE TO BOTH OPPORTUNITIES:

Expenses: Travel expenses will be paid accordance to CRUK's travel expense policy. An optional payment of £100 per day will be offered in recognition of your contributions.

Equal Opportunities: At CRUK we value diversity and we're committed to creating an inclusive environment which facilitates the involvement of all people affected by cancer. We actively encourage applications from people of all backgrounds and cultures. In this role you may work with and will need to represent the views of a diverse group of people.
YOUR SKILLS AND EXPERIENCE
We are looking for people who:

- Are or have been affected by children and young people’s cancer (this includes patients, survivors, young people, parents, guardians, carers, etc.)
- Have a keen interest in and a basic understanding/experience of research and/or clinical trials
- Can think strategically
- Take a solutions-based approach to problems
- Feel comfortable talking about research, clinical trials and their cancer experience where/if relevant
- Can participate in active conversations with a range of people
- Have good communication skills and the confidence to share their thoughts constructively
- Have the ability to listen, understand and respect different opinions
- Can represent the needs and voice of a broad range of people.

You do not need to have:

- Any prior knowledge of Cancer Research UK
- Participated in a clinical trial
- Experience as a researcher.

YOUR ROLE
You will be required to:

- Attend and take an active part in group meetings, contributing thoughtfully and constructively to discuss your views
- Review any pre-reading material ahead of meetings to support your participation in discussion
- Work with the Cancer Research UK staff responsible for the group meetings to develop and refine the patient representative role within the group
- Represent the broader patient and parent community alongside your own perspectives
- Respect Cancer Research UK’s confidentiality, non-disclosure and conflict of interest agreements.

WE WILL SUPPORT YOU BY

- Providing you with a key contact at Cancer Research UK who will answer any questions you have about your role.
- Offering you a welcome phone call from the Cancer Research UK staff member who manages the steering group to answer any queries.
- Creating a safe and open environment for feedback, so that you can share your views about how the group is working and suggest improvements.
- Providing timely, clear and easy to understand information about the content to be discussed at the meetings to make it easy for you to understand and share your opinions.
- Asking for your feedback to understand and improve your experience of the role.
- Provide emotional support via our Cancer Research UK nurses if needed.

HOW TO APPLY
- Please contact involvement@cancer.org.uk if you have any questions.
- Complete an application and return it to involvement@cancer.org.uk by 9am on Monday 18th May.
- Shortlisting will take place during week starting 18th May.
- Telephone interviews will take place during the week beginning 25th May.
- If successful, you will start your role:
  - Opportunity 1 (Cancer Research UK (CRUK) Children and Young People Steering Group): September 2020 (meeting date to be confirmed), probably via teleconference.
  - Opportunity 2 (Experimental Cancer Medicines Centre (ECMC) Paediatric Strategy Group): first meeting held via teleconference on 2nd July 2020.