



**Solving
Kids'
Cancer
UK**

**RECRUITMENT PACK
Parent Involvement
Forum Role**



We are fighting for a future where no child dies of the childhood cancer neuroblastoma or suffers due to the treatment they receive



Welcome

We're delighted that you're interested in volunteering as a Parent Involvement Forum (PIF) member for Solving Kids' Cancer UK. Included in this pack is some information to help you get to know the charity better as well as details about the role.

Solving Kids' Cancer UK is a very special charity with a dedicated and passionate team of staff, trustees and volunteers. We are proud of our parent-led ethos - we have parents with lived experience of neuroblastoma working at every level of our charity, from volunteers to employees, to our Board of Trustees. Our PIF members play a very important role in ensuring the voice of parents (and by association children and young people) is heard and centred in our work, helping ensure we remain focused on addressing the challenges faced by the people who need our support most. All volunteers freely devote their time, energy and passion for helping other families to support Solving Kids' Cancer UK to make the greatest impact for children and families affected by neuroblastoma.

It's an exciting time to be volunteering as a PIF member as we continue driving forward our current five-year strategy. Over the coming years, Solving Kids' Cancer UK will remain neuroblastoma focused, but with flexibility to operate in support of children with cancer more broadly, where doing so will have the greatest potential impact - including for children with neuroblastoma. We will work with existing and new partners, to launch our most ambitious research funding award to-date with a focus on accelerating more effective treatments. We aim to reach all families of children diagnosed with neuroblastoma in the UK, providing a broader range of practical, emotional, and financial support throughout their journey. And we will continue to advocate for children and families affected by childhood cancer, having recently developed our first Public Affairs strategy, to more boldly champion the needs of children diagnosed with neuroblastoma and other childhood cancers.

If you're excited about joining us on this journey towards our vision where no child dies from the childhood cancer neuroblastoma or suffers due to the treatment they receive, please consider expressing your interest in the role.

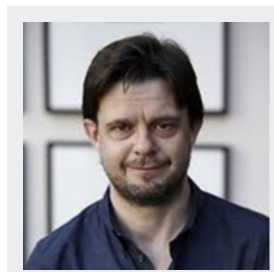
We look forward to hearing from you.

Gail Jackson | Chief Executive Officer

Nick Bird | Chair of Board of Trustees

A handwritten signature in black ink, appearing to read "G Jackson".

A handwritten signature in black ink, appearing to read "N Bird".



About Solving Kids' Cancer UK

Solving Kids' Cancer UK is a small but mighty charity with children firmly at its heart. We are fighting for a future where no child dies of the childhood cancer neuroblastoma or suffers due to the treatment they receive.

Neuroblastoma is a rare and complex childhood cancer. Around 90% of neuroblastoma cases occur in children younger than five years of age, making it the most common cancer in infants. The work of Solving Kids' Cancer UK is parent-informed and we develop our services in response to the needs of the community we work with.

Our organisation is passionate about speeding up pioneering clinical research that will save lives and improve outcomes for children. Our advocacy work within the neuroblastoma research world means we are uniquely placed to use our influence and reputation alongside our accredited research funding framework to make a difference for children now and in the future.

Our Family Support Service provides emotional, practical and financial support, and impartial information on the latest treatments available, and where appropriate supports families to access treatment options for their child that are not currently available on the NHS.

We are a voice for children and their families. In every conversation we amplify their voice and ensure children are at the heart of all we do. We will not stop until children with neuroblastoma, in the UK and beyond, have access to the treatment they need, when they need it.



Our vision, mission and strategy

Vision

A future where no child dies of the childhood cancer neuroblastoma or suffers due to the treatment they receive.

Mission

Helping those affected by neuroblastoma, an often aggressive and deadly childhood cancer, by

- **Initiating and funding** best-in-class clinical research
- **Providing hope**, information, and support to families throughout their cancer journey
- **Raising awareness** of childhood cancer, advocating and campaigning for positive change.

Strategy

Our strategic plan 2022 - 2027 has been informed by our stakeholders and developed in line with our vision; ensuring we have a blueprint for our growth, sustainability and stability into the future. Our strategy is driven by three key pillars: **Research, Support and Awareness.**

STRATEGIC PLAN 2022-2027



We are fighting for a future where no child dies of the childhood cancer neuroblastoma or suffers due to the treatment they receive.



Our strategy

To underpin the delivery of our five-year strategy, our work will be guided by an internal implementation plan centred around three key enablers and a clear focus on our vision and values.

Sustainable

We will ensure our charity remains financially robust to deliver against our strategic objectives, securing the funds required.

Good governance

We will continue to build a strong culture of compliance, transparency and continuous improvement at all levels of the organisation.

Impact

We will measure and showcase the impact of our work and demonstrate return on investment to our supporters.

Our work is driven by three key pillars

Research

Accelerate clinical trial development

We will focus on the development of new treatments by investing in clinical research and working with valued partners for maximum impact.

Prioritise the needs of children

We will engage with families to identify areas of unmet need, challenging experts to find solutions and work together to deliver maximum impact through the research we fund.

Foster collaboration

We will build and strengthen international partnerships to share expertise, best practice and resource, whilst building knowledge.

Support

Reach ALL families

Every family of a child diagnosed with neuroblastoma in the UK will have access to our support service from the point of diagnosis.

Broaden range of support

We will develop and expand our support offer in line with what families tell us they need.

Inform and support decision making

We will ensure families have access to the most current and scientifically robust data from around the world and support their decision to access the best treatment possible.

Awareness

Research advocacy

We will amplify the voice of the children and parents, seeking to advance science and understanding of the disease alongside patient-centric research.

Patient advocacy

We will champion the needs of individual children and their families, providing parent-led support around decision-making to improve treatment outcomes.

Awareness and campaigning

We will raise the profile and support the treatment needs of children with neuroblastoma and other childhood cancers with the general public, government and public bodies.

Our values

**Caring
Transparent
Collaborative
Inclusive
Determined
Hopeful**



**Solving
Kids'
Cancer
UK**

Our values



Transparent

We are open and honest about all that we do and how we do it.



Caring

We care passionately about children with neuroblastoma and their families and all those who care for them, including our staff, volunteers and supporters.



Collaborative

Relationships are at the heart of our work – from the children and families we work with to the individuals, organisations and networks that are involved in their care.



Inclusive

Our services are developed to ensure they meet need and we aim to make them accessible to all.



Determined

We lead with tenacity and are unfaltering in our drive to help, support and fight for children with cancer.



Hopeful

We have a strong sense of optimism and hope is at the heart of all that we do.



Our team and structure

Board of Trustees

Chair
Nick Bird

Treasurer
David Coulon

Matt White

Aine McCarthy

Joey Tabone

Alex Lane

Chief Executive

Chief Executive Officer
Gail Jackson

Executive Assistant
Georgina Clark

Finance

Director of Strategic Finance
Gemma Wadsley

Senior Finance Manager
Sue McGregor-Ogden

Finance Officer
Ed Fordham

Finance Assistant
Val Wood-Brignall

Operations

Head of Operations
Claire Hislop

Database Manager
Nicholas Leverton

Family Support

Head of Family Support Services
Vicky Inglis

Family Support Coordinator
Hayley Blackwell

Family Support Coordinator
Samantha Wilkinson

Research & Awareness

Head of Research
Leona Knox

Research Manager
Leah Ambler
(maternity leave from Oct 2024)

Public Affairs & Advocacy Lead
Emily Hall

Research Manager
Stephanie Restivo
(maternity cover)

Fundraising and Engagement

Head of Fundraising & Engagement
Danielle Russell

Fundraising Campaigns & Comms Manager
Laura Nott

Relationship Manager
Anna Austin

Communications & Campaigns Manager
Laura Barker

Fundraising Manager
Vacant

Community & Events Fundraising Manager
Sophie Anderson
(maternity leave until Oct 2024)

About the Parent Involvement Forum

Our Parent Involvement Forum (PIF) was launched in 2021 and includes a cross-section of parent representatives with children affected by neuroblastoma. The role of the PIF is to ensure that the voice of parents (and, by association, children and young people) is always heard and informs the charity's activities and support. Members attend virtual meetings every quarter when they are expected to share their views and ideas, helping the charity to shape its projects and plans.

We always aim to ensure that members combined represent the diversity of the neuroblastoma patient-parent community and specifically, children diagnosed with low, intermediate or high-risk neuroblastoma; accessing frontline NHS treatment; accessing a clinical trial outside of the UK, as well as families that have received a support service from SKC UK; engaged in a fundraising campaign via SKC UK; and are geographically spread across the UK and Ireland.

For more information about the PIF and its current members, visit our [website](#).



“I’ve found attending the group a very useful, informative and fulfilling activity. It has felt very important to give back when we’ve been so fortunate with [my child’s] health.”

Parent member

Key role information

Role title	Parent Involvement Forum member
Location	Virtual / home-based
Hours (indicative)	Four meetings per year (one and a half hours each) plus meeting preparation
Salary	Voluntary role
Contract type	Initial 2-year term, renewable for another 2 years

What we provide to members

- Induction session to prepare you for the role, including named current PIF member to connect with
- Safe and comfortable space during meetings with sensitive facilitation
- Manageable group size to allow time for each member to contribute
- Individual courtesy check-in meeting for new members within first year of term
- Opportunities to participate in training
- Ongoing support and guidance from the Family Support Service team
- Opportunities to network with other people affected by neuroblastoma at various events
- Regular updates from SKC UK on the progress of our programmes of work
- Transparency and honesty about what we can and cannot achieve
- Use of plain, jargon-free language in meetings and an explanation of all acronyms
- Access to information, including meeting papers, in good time to allow for preparation
- Signposting to additional sources of support if needed - we understand that talking about childhood cancer can be difficult. Members can take a break at any point, including during a meeting if required.



Role description and terms of reference

Objectives of the Parent Involvement Forum

- Obtain parent input which is representative of as diverse a range of parent and child experiences as possible, to establish ways to improve the service children and their families receive
- Consult parents on specific components of the services offered by the charity in order to enhance how they are developed and delivered
- Work with parents on specific projects as determined by the charity
- Leverage development and experience of parents within the Parent/Patient Advocacy landscape

Parent Involvement Forum role activities

- Prioritise attendance at virtual meetings and contribute effectively by reviewing the information sent in advance, listening and contributing to discussions, hearing other's views and raising key, relevant issues from a wider patient and carer perspective
- Ask questions and enquire how our plans and programmes of work will impact on the way other parents access and use the service being designed
- Consider the needs of different communities of people affected by neuroblastoma when helping us shape services
- Be collaborative, inclusive and respectful when working with us and other people affected by neuroblastoma ensuring to uphold our charity's values
- Refrain from behaviours and style of communication which may be perceived as, discriminatory, unfair or unconstructive to the members of the group
- Respond to email requests promptly and to let us know in advance if you are not able to attend meetings or other key events
- Sign a confidentiality agreement and respect the confidential nature of some aspects of the meetings
- Declare any potential conflicts of interest as they arise.

Parent members are encouraged to:

- Talk to other parents to pick up comments and concerns in the community, whilst respecting the confidentiality of any individual
- Promote the work of the charity sharing feedback and knowledge gained within community networks
- Take advantage of any training and development opportunities provided

Role description and terms of reference cont.

Role requirements

For this role, it's essential to be:

- Passionate about supporting us through a positive dialogue and a collaborative approach
- Able to consider issues beyond your own experience of services and anecdotes
- Willing to provide objective input about the needs of children and parents affected by neuroblastoma and to represent the diverse range of people diagnosed with this disease
- Able to communicate your ideas to a wide range of people
- Confident about participating in group discussions and presenting the views of people affected by neuroblastoma
- Able to offer constructive challenge when necessary
- Able to listen to and respect different perspectives and display empathy
- Able to understand and evaluate a range of information and evidence to support different approaches to service delivery
- Aware of and commitment to equity, diversity and inclusion
- Reliable and able to meet the time commitment outlined above, including preparing for meetings
- Willing to adhere to our charity values, Conflict of Interest Policy and sign a Confidentiality Agreement.



“I think the PIF is a really effective and valuable forum. Vicky your facilitation of the meetings has been brilliant! Really pleased to see it evolving. It seems the right way forward to me. It's strength is definitely in hearing the different viewpoints and opinions.”

Parent member

Recruitment timeline

We aim to keep to the timetable outlined below.

Expressions of interest open:

Tuesday 20 August 2024

Expressions of interest close:

8 September 2024, 11:59pm

Selection and decision making:

September 2024

Once all expressions of interest have been received and reviewed, you will be contacted by Vicky, Head of Family Support Services. You may be invited to speak with Vicky and Gail, our CEO, prior to a final decision being reached. If more expressions of interest are received than member places available, those who represent children and families not already represented through members combined will be prioritised.

How to apply

Please complete and submit an **Expression of Interest Form** highlighting why you would like the role and what you think you could bring to the group.

We also invite you to complete and return an anonymous **Diversity Monitoring Form**, which is an online form accessible **here**. The information contained in the questionnaire will be treated as confidential and will be used to monitor and drive our work towards our diversity and inclusion commitments.

If you would like an informal conversation with **Vicky Inglis, Head of Family Support Services** before expressing interest in the role, contact vicky@solvingkids cancer.org.uk

If there are any adjustments that would help you to engage with this process, please let us know.



We are an equal opportunity charity

We welcome and invite applications and expressions of interest from all suitably qualified individuals, regardless of age, disability, gender or gender reassignment, marriage/civil partnership, pregnancy, maternity, race, religion or belief, sex or sexual orientation. We invite you to let us know how we can help you to better engage with the recruitment process.

We are a safeguarding charity

Our work and practice are underpinned by safeguarding principles with the aim of protecting children and young people and enhancing their welfare. Solving Kids' Cancer UK always works in accordance with legislation, statutory guidance and best safeguarding practices.

We are a parent-led charity

Solving Kids' Cancer UK is a parent-led charity and actively encourages applications and expressions of interest for jobs and voluntary roles from the parent community with lived experience of neuroblastoma and/or other childhood cancers.



solvingkidscancer.org.uk



[Solving Kids' Cancer UK](https://www.linkedin.com/company/solving-kids-cancer-uk)



[SolvingKidsCancer365](https://www.facebook.com/SolvingKidsCancer365)



[skc365](https://www.instagram.com/skc365)



[SKC_UK](https://twitter.com/SKC_UK)

Solving Kids' Cancer UK is a registered charity in England and Wales (1135601), and in Scotland (SCO45094).