



# Solving Kids' Cancer

## Strategic Plan 2017-2022 Executive Summary

Following a comprehensive review of its direction and activities, undertaken in 2017, Solving Kids' Cancer has produced a blueprint for its work over the next 5-year period.

The charity will focus its efforts on improving the lives of children and families affected by the childhood cancer neuroblastoma, a deadly disease that affects predominantly young children. 90% of neuroblastoma cases occur in under-5s with a median age at diagnosis of 19 months. Neuroblastoma has a 5-year survival rate of just 68%, versus 83% for all childhood cancers combined.

The *name, vision, mission, and key priorities* of the charity were thus agreed:



# Solving Kids' Cancer

*Advancing science; empowering parents; defeating neuroblastoma.*

**Vision:** "A future where no child dies of (the childhood cancer) neuroblastoma and no child suffers due to its treatment."

**Mission:** "Helping those affected by neuroblastoma, an often aggressive and deadly childhood cancer, by:

- Facilitating access to treatment in partnership with clinicians and researchers,
- Advancing science through investment in clinical research,
- Advocating for more effective and less toxic treatments,
- Providing hope, information, and support to families throughout their journeys."

### **Priorities:**

1. Strengthen governance to successfully deliver the charity's mission.
2. Engage and inspire long-term public support in the charity and fight against neuroblastoma.
3. Review and enhance the charity's support offerings.
4. Facilitate access to the best available treatments and most promising clinical trials.
5. Support and enable best-in-class clinical research, accessible in the UK.
6. Harness the combined power and resources of the neuroblastoma community to most effectively advocate for, and work in support of, children and their families.

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## **Strengthen governance to successfully deliver the charity's mission**

It is vital that Solving Kids' Cancer has strong governance in place to enable the charity to not only achieve its strategic objectives to benefit children with neuroblastoma; but also ensure it meets its legal requirements, delivers best practice in terms of data protection and information governance, and fully develops the potential of all its staff and volunteers. It must strengthen, grow, and diversify its Board of Trustees, other volunteers and its team of professional staff. It must renew systems, and develop processes, that enable the organisation to work in a more effective and efficient manner.

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## **Engage and inspire long-term public support in the charity and fight against neuroblastoma**

The charity occupies a unique position in the neuroblastoma landscape. Our links to families, relationships with medical professionals, extensive understanding of the neuroblastoma world, and international connections makes us well placed to take a leading role in improving the health of children afflicted by this terrible disease, and in helping their families better navigate the tortuous journey through it.

The current operating model of the charity, however, requires significant changes if we are to fulfill this potential. We must develop a successful and sustainable undesignated general income generating platform to provide the future funds to enable the charity to grow and achieve its aims. This will require us to expand our fundraising team and capability, develop compelling narratives to support our cause, engage and retain support from diversified fundraising sources, and build better and closer relationships with both families and potential donors.

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## **Review and enhance our support offerings**

The charity will seek to build on the work that it currently does through its *Care And Connect* service, to enhance the support that it offers to children and families affected by neuroblastoma. We will work to expand the scope of our support to include all children and families affected by neuroblastoma in the UK, including those with low and intermediate risk disease. We will develop stronger links with other charities offering financial, emotional and practical support, to complement our own services, and seek to offer enhanced support for those families travelling to overseas institutions for treatment. We will continue to explore our role within the Republic of Ireland, given its proximity and close links to the UK, in particular with its designation as a CCLG primary treatment centre.

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## **Facilitate access to the best available treatments and most promising clinical trials**

We will use our experience, expertise and professional network to help facilitate access to treatment for all children with neuroblastoma who seek our help. We will work with families, medical professionals and others to ensure all children can access the most effective evidenced based care and, where appropriate, clinical trials – wherever possible within the UK, but if needs be overseas.

We will work to raise the level of specialist neuroblastoma knowledge amongst the wider clinical community in the UK, and seek to ensure that children throughout the UK have an equal opportunity to access the best available treatments, as close to home as possible. We will work to ensure that

every parent has access to the information they need to participate in meaningful dialogue with clinicians, and make informed decisions regarding their child's treatment. Our ambition is for Solving Kids' Cancer to be known by all as an authoritative, reliable and trustworthy source of information, demonstrating intelligence, integrity, and impartiality. We will build on the success and reputation of our annual Neuroblastoma Parent Education Conference, and explore other opportunities for engaging, informing, and empowering the parent community. We will advocate on behalf of children with neuroblastoma; campaigning, educating, lobbying, and influencing policy decisions to bring about positive change.

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### **Support and enable best-in-class clinical research accessible in the UK**

We will play a leading role, working in partnership with prominent researchers and clinical experts, and bringing insight from those impacted by neuroblastoma; to increase, shape, and accelerate UK-based neuroblastoma research. To maximise access and potential benefit for UK children, both those currently affected and those yet to be diagnosed.

We will assemble a Scientific Advisory Board of international standing to develop and oversee a proactive research strategy; identifying unmet clinical needs, and working to maximise the impact and value of the research investments we make.

The charity's research effort to defeat neuroblastoma will be two-fold. For children fighting neuroblastoma today, we will work to increase and improve the available treatment options; resulting in more children living longer with their disease, and more children being cured of it. For children yet to be diagnosed, we will work to advance the scientific understanding of the disease and support the development of more effective and less toxic therapies; to improve cure rates, and reduce the cost of cure in terms of treatment-related health problems.

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### **Harness the combined power and resources of the neuroblastoma community**

We must seek opportunities to maximise the collective impact of the neuroblastoma community on research, treatment and support by building meaningful partnerships with all key stakeholders both domestically and internationally. These include, but are not limited to; parents, charities, clinicians, researchers, and the NHS. We will identify and pursue opportunities to collaborate better with other charities, clarify our relationship with Solving Kids' Cancer in the US, and develop improved relations and strategic partnerships with key clinical staff and healthcare institutions of international repute.

We will work to represent children and families affected by neuroblastoma, advocating for positive change, providing a platform through which parents' voices can collectively be heard. Not only is neuroblastoma a rare disease, but those affected are too young to speak for themselves. Solving Kids' Cancer needs to become their voice.

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Delivering this action plan will not be straight forward. It is an ambitious blueprint for future work; requiring significant changes, generation of funds and commitment from all. Like any charity, Solving Kids' Cancer has access to finite resources. Coupled with the significant challenges that need to be addressed, the charity faces an intense period of concerted effort if it is to succeed in its endeavours.