### CCLG: The Children & Young People's Cancer Association research:

# Understanding treatment decision-making processes in families where a child or young person has relapsed or refractory rhabdomyosarcoma

**Project title:** Understanding treatment decision-making processes in families where a child or young person has relapsed/refractory rhabdomyosarcoma

**Project stage:** Complete (ended August 2024)

**Funded by:** CCLG and CCLG Special Named Funds including Angus' Door, Jacob's Join, Pass the Smile for Ben, Ollie's Star, Be More Ruby and Team Jake.

**Led by:** Professor Bob Phillips, University of York

## About the project

In children whose rhabdomyosarcoma has not responded to treatment (refractory), or has come back after treatment (relapsed), there are difficult decisions to be made about what treatment to give. Only around one in five children with relapsed or refractory rhabdomyosarcoma can be cured, and so there are choices to be made about how to proceed. The options might include:

- Aggressive treatment aiming to cure
- Treatment to reduce the amount of disease, and therefore help symptoms
- Experimental trials of new treatments (also called early phase studies)
- Symptom control

Families may never know what the best option would have been and can spend years wondering what might have happened if they had chosen differently. In this project, Prof Bob Phillips' team will conduct two linked studies to help understand how decisions are made about treatments:

1. A "systematic review", where the researchers will look for all previous early phase studies in relapsed or refractory rhabdomyosarcoma and see how effective the different new treatments are for different children. This will help to give families and professionals more accurate information about what to expect from the options available.
2. An interview study, where the team will speak to patients and families about how they have made, or are making, decisions about treatment in relapsed or refractory rhabdomyosarcoma. This will help us understand the decision-making process and how best to support families making these choices.

The results of both of these studies will be combined in a best practice statement which will provide advice and support to clinicians and families about important things to consider when discussing treatment options. The project will include patients and parents in designing and performing the research to get the best results for families in the future.

## Results

Overall, the team found 129 published studies during the systematic review, which included over 1,100 patients with relapsed and refractory rhabdomyosarcoma. The studies included multiple treatment types of treatment. The researchers also identified 99 relevant clinical trials. You can find out more about the review findings, and the follow on Living-REFoRMS project, here: tinyurl.com/REFoRMS-projects

Prof Phillip's team interviewed 7 mothers and 6 fathers about their experiences of making decisions for their child, resulting in over 17 hours of interview recordings and 8 completed Lifegrids (which are a timeline of a child's treatment, written by parents). The researchers are working to prepare this data for publication, but have identified four main themes from parents when making treatment decisions and one over-arching theme for parents of 'doing their own research'.

Summary of the four themes:

- Trust in provider – trust in their consultant and clinical team's expertise led parents' decision-making, but relapse sometimes felt like a betrayal of this trust.
- Feeling that you just have to do something – parents described the need to look for new treatment options, looking at treatments for other cancers, international options, and early phase research. This could cause disagreements and pressure between parents.
- Family's social network for cancer – both online and offline, parents looked for other children and young people with the same disease to help inform their decision-making, even contacting other parents to discuss treatments. This could be very helpful, but created feelings of obligation and discomfort around sharing negative treatment responses.
- Distinction between living and being alive – time in hospital versus time at home, and the ability to join in with normal activities, was often a key concern for parents. Parents wanted a high quality of life for their child's remaining time, and turned down treatments that they felt their child would struggle with.

These themes are explained in the team's video: jtvcancersupport.com/2025/05/the-reforms-project

## What's next?

The team are working on a publication to share the results of the interview study. The systematic review became a 'living systematic review' called Living-REFoRMS that has been regularly updated with the latest trials and results for relapsed and refractory rhabdomyosarcoma. This was funded by CCLG Special Named Funds until recently, and the researchers are currently looking for further funding to continue providing up to date summaries for families and clinicians.

Be more Ruby

Pass The Smile

Ollie's Star

Team Jake

Jacob's Join
For research into rhabdomyosarcoma

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