



Sara Wakeling

Patient Advocate

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Sara is a Research Assistant at the Louis Dundas Centre for Children's Palliative Care at the UCL Great Ormond Street Institute of Child Health in March 2020. Her role, as a Research Assistant, has a particular focus on parental and patient involvement (PPI) within research.

Sara's eldest daughter, Alice, was treated at Great Ormond Street Hospital for the childhood cancer, rhabdomyosarcoma. Alice battled with the disease for almost 5 years, relapsing twice and having two periods of remission before passing away in October 2019, aged 7. Alice also received proton radiation at the UF Health Proton Therapy Institute in Jacksonville, Florida, chemotherapy at Wolfson Children's hospital, Jacksonville, Florida and AMORE (surgical resection, brachytherapy and surgical reconstruction) at the Emma Children's Hospital, Amsterdam. The Palliative Care Team at Great Ormond Street Hospital provided comfort care for Alice in her last few months. Alice's journey with cancer means that Sara can bring her experience of parenting a child with a serious illness to help inform the team's research projects.

Sara has been a member of the European Paediatric Soft tissue sarcoma Study Group (EpSSG) parent group since December 2020. This involves attendance at the FaR-RMS trial steering committee meetings, reviewing parent documentation as part of FaR-RMS and working/advising on visual aids communicating the details of FaR-RMS. One particular project included devising a logo to represent the FaR-RMS trial in conjunction with young cancer survivors, clinicians, scientists and families.

She is also the co-founder and CEO of children's cancer charity, Alice's Arc. The charity aims to find a cure and better treatments for rhabdomyosarcoma by working with centres of excellence like the Institute of Cancer Research (ICR), Wellcome Sanger, The University of Birmingham, Great Ormond Street and the Royal Marsden. It also has a family well-being arm that provides support for families at any stage of the illness trajectory.

Prior to Alice's diagnosis, Sara had a career in marketing within the professional services sector. She has a Certificate of Higher Education in Counselling & Counselling Skills from Birkbeck College, University of London and is currently studying for a Certificate in CBT for Children and Adolescents. Sara has a BA (Hons) Educational Studies, University of York.

Her current research projects include PPI for a perinatal & antenatal decision-making study where a serious heart defect is detected in a baby, PPI for a decision-making study exploring parenting a terminally ill child and PPI regarding parental health and well-being.