

# Sarcoma UK

An introduction

Ian Hughes



# Sarcoma UK Trustee



- Trustee at Sarcoma UK for 7 years - this is my penultimate year
- Meet four times a year with subsidiary meetings in between covering HR, Finance and Research Funding
- Particular interest is communication, income and overall strategic objectives for the charity

## Role of a trustee

*To ensure good governance and manage the direction and activities of the charity.  
Make sure the charity operates with independence and within the law.*

*As a trustee, we aim to bring a specific set of skills and experience to help the charity meet its' objectives*

# My cancer timeline



- Prior to 2010 (aged 40) no health issues
- 2010 leiomyosarcoma left ankle
  - From GP to resection at Birmingham Royal Orthopaedic – 5wks (private/NHS)
- 2012 basal cell carcinoma
- 2014 our son, Oscar, died of medulloblastoma
- 2017 retroperitoneal leiomyosarcoma
  - From diagnosis to treatment (4wks) at Leeds Regional Sarcoma Centre
  - Three chemotherapy cycles (Leeds NHS) and resection at Royal Marsden (private)
- 2018 Li-Fraumeni Syndrome (LFS) diagnosis via Prof Ros Eeles (Royal Marsden)
  - Current observation protocol via Prof Gareth Evans (Christie)
  - In 2018 we confirmed Oscar had mutated TP53

# What is sarcoma?

- Sarcoma is a type of cancer.
- 15 people a day will receive a diagnosis of sarcoma cancer in the UK.
- They can develop anywhere in the body, including the muscle, bone, tendons, blood vessels and fatty tissues.
- There are around 100 sub-types of sarcoma.
- Sarcoma UK is a national charity that funds research, offers support and campaigns for better treatments.





# Our Information

- Information we provide is patient focussed, driven by patient need and reviewed by them
- 13,000 sarcoma information booklets/factsheets downloaded in 2017-18
- Eight in 10 people tell us we've answered their questions about sarcoma.\*

\*Sarcoma UK poll

Dec 2017-June 2018, 2784 respondents



# Support for everyone affected



- Launched in 2016, confidential and independent support line staffed by specialist sarcoma nurses
- There to listen, help and point you in the right direction
- To date more than 3400 contacts with users



[supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)

# How Sarcoma UK can help



- Up to date information and support for patients and carers
  - Clinical Advisor and Professional Review Panel
- Specialist Sarcoma Centres & Multi-Disciplinary Teams (MDT)
  - Links on referrals to these centres
- The Clinical Trials Hub
  - Database of current sarcoma clinical trials
  - Supporting patient access
- Information for Health Professionals
  - First line for early diagnosis - Diagnostic tool kits
- Sarcoma Support Line
  - Specialist sarcoma nurses

