

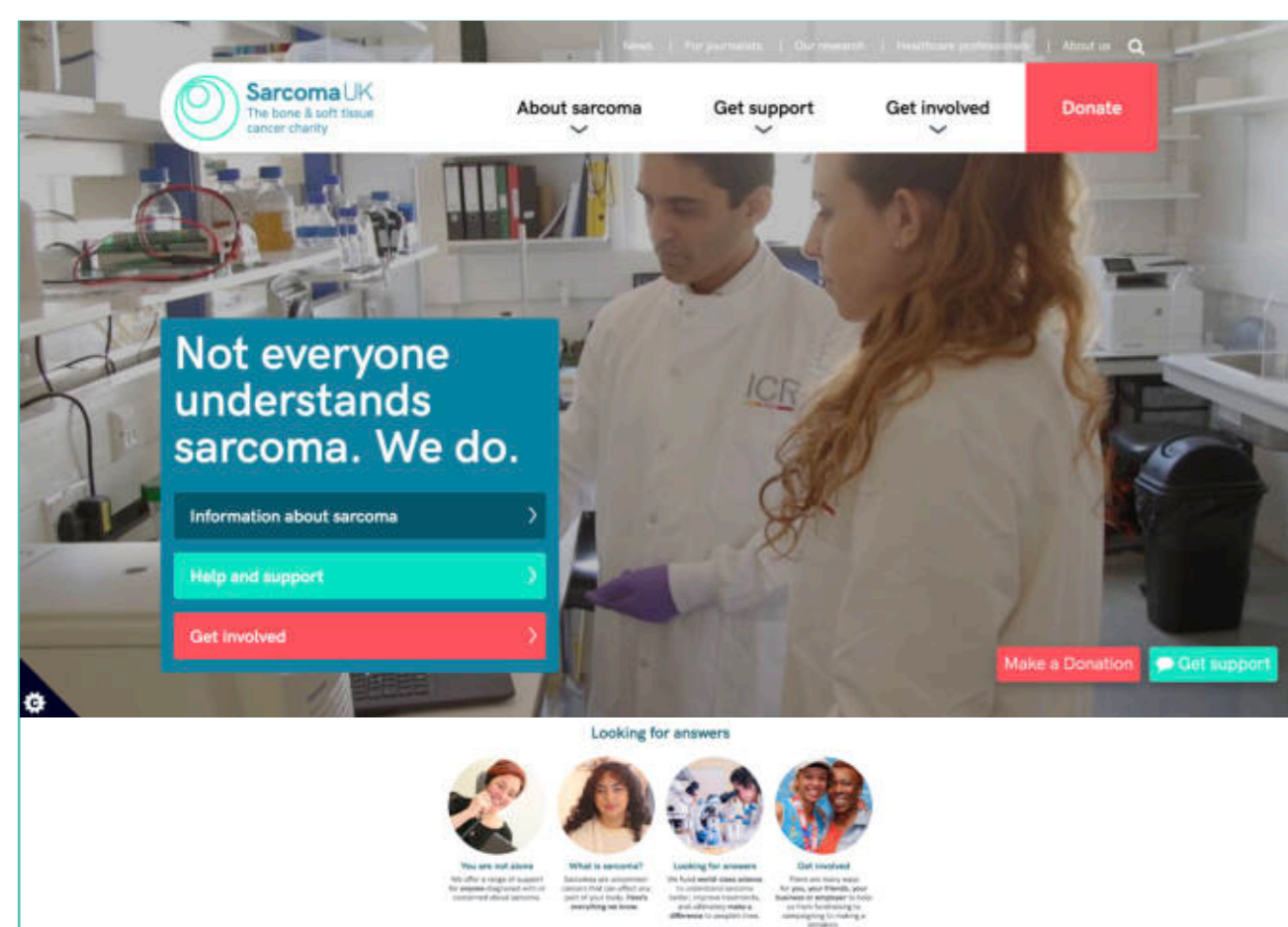
Sarcoma UK

Our mission is to ensure everyone affected by sarcoma receives the best treatment, care, information and support available and to create the treatments of the future

Sorrel Bickley, Director of Research, Policy and Support
Correspondence: sorrel.bickley@sarcoma.org.uk

Who we are

- Sarcoma UK was founded by Roger Wilson CBE, a sarcoma patient.
- We are the only cancer charity in the UK focusing on all types of sarcoma.



What we do

Guided by our strategy *Tackling Sarcoma Together*, we:

- Find answers through funding sarcoma **research**.
- Drive **awareness** of sarcoma cancer.
- Provide **information** and **support** to anyone affected by sarcoma.
- **Campaign** for better treatments and to improve standards of care.
- **Fundraise** to help us continue our work



Patient Involvement

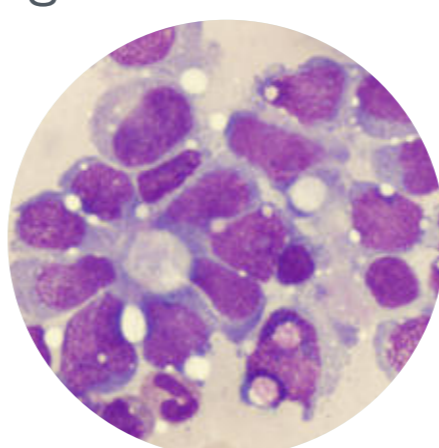


- We want to make sure the voice of people affected by sarcoma is heard throughout the organisation and within the Sarcoma community.
- Our Patient Involvement Network is made up of people affected by sarcoma who want to shape our work
- The Network now has over **120 members**
- Opportunities offered include:
 - ▶ Reviewing research proposals
 - ▶ Joining recruitment interview panels
 - ▶ Reviewing information resources
 - ▶ Joining focus groups

Research



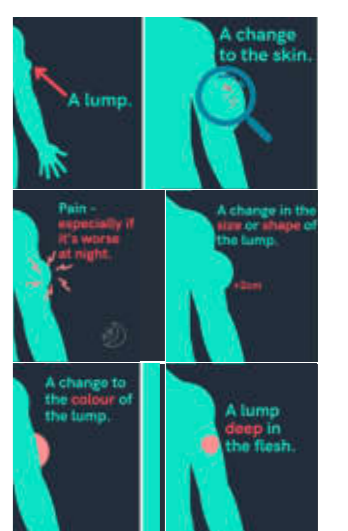
- Since 2009, we've invested over **£5 million** into research across the UK
- We fund research into:
 - ▶ Cause
 - ▶ Diagnosis
 - ▶ Treatment
 - ▶ Quality of life
- We offer small, large grants and PhD Studentships
- We prioritise collaboration and fund research in partnership with LifeArc, GIST Cancer UK, the Bone Cancer Research Trust and the Grace Kelly Childhood Cancer Trust
- We target our research funding into areas of patient priority including:
 - ▶ Genomics
 - ▶ Diagnosis
 - ▶ Ultra-rare subtypes
- Our research funding has led to over **140 publications and presentations**, and over £5 million of follow on funding for sarcoma researchers



Policy



- Our Policy Priorities:
 - ▶ Earlier and more accurate diagnosis
 - ▶ Access to the best possible care
 - ▶ Access to appropriate psychological support
- Our 2020 report, *Delays Cost Lives* calls on policy makers to improve early diagnosis of sarcoma
- We have launched a new sarcoma education module for GPs and new Signs and Symptoms resources for people concerned they have sarcoma



Support



- The Support Line is staffed by healthcare professionals with expertise in sarcoma
- The team can be contacted by phone, email and text
- We've been in contact with almost 5,000 individuals

Top 3 reasons to contact the Support Line:

1. Emotional support
2. To discuss treatments
3. Questions pre-diagnosis

Information



- We publish digital and print information for people affected by sarcoma and healthcare professionals
- In the past 12 months we've sent out **18,256 print information resources**
- We've published a soft tissue sarcoma data hub to help people to see where their subtype fits in
- We have a clinical trials hub to allow people to search for and find trials for their sarcoma subtype.

