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# Sarcoma research fund update

## Summer 2017



Sarcoma represents just 1 per cent of all adult cancers. As a result, progress in sarcoma research and treatment development has been slower than in more common cancer types. This means the need for increased funding in sarcoma research has never been higher.



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### World-leading sarcoma treatment and research

As a specialist cancer hospital, we receive a high number of sarcoma patient referrals. The Sarcoma Unit at The Royal Marsden now registers more than 850 patients a year.

We have an incredibly experienced, multi-disciplinary team of specialist doctors, nurses and allied health professionals working at the Sarcoma Unit at The Royal Marsden. This combination of high patient numbers and established research infrastructure mean that we are ideally placed to make a major contribution to sarcoma research nationally and internationally.

The Sarcoma Research Fund was established to provide support for research into the treatment of sarcoma. All donations to the fund support the entire work of the unit. This includes the funding of trial-specific staff, such as clinical research fellows, research nurses, trial co-ordinators, data managers, administrative staff and tissue collectors, all of whom contribute enormously to the successful running of the unit:

- Research nurses are vital to the day-to-day running of clinical trials. They lead on patient recruitment, gaining informed consent, and monitoring treatment. Often the point of contact, they provide valuable support to the patients on studies as well as their families. They also use their knowledge and experience to advise researchers who are devising new study protocols, helping them to gather the necessary data, while taking into consideration the needs of the patients.
- Trial co-ordinators are experts in ethical, legal and regulatory requirements, lead on the set up and delivery of trials, and ensure reliable data collection.
- Administrative staff provide key support to both the clinical and the regulatory teams, ensuring all aspects of the department's work are run in a timely and efficient manner.
- Tissue collectors manage the collection and tracking of blood/tissue samples for analysis, from patients at The Royal Marsden and around the country.
- Clinical research fellows conduct research on the biology of sarcomas and look at better ways of treating and supporting sarcoma patients.



In spring 2017, Consultant Histopathologist Dr Khin Thway (pictured above, right) received the 2017 Arthur Purdy Stout Society Annual Award. The award recognises significant career achievements by young surgical pathologists whose research publications have had a major impact on diagnostic pathology.

This is a prestigious honour for Dr Thway, who is the first person outside the US to receive this award. It demonstrates the lead role the Unit is determined to take to improve outcomes for sarcoma patients.

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### New approaches in sarcoma: classification and treatment

Historically, the many different types of soft tissue sarcoma have been characterised by the tumours' appearance under a microscope. Increasingly, more sophisticated molecular techniques are used, thus allowing for more accurate diagnosis and better informed management.

Dr Alex Lee, medical oncology trainee in The Royal Marsden's Sarcoma Unit, is working towards a PhD project aimed at developing new means of biology-driven categorisation of soft tissue sarcomas. Areas of particular interest to Dr Lee include how the body's immune system interacts with sarcomas as they develop and how this might influence the disease's behaviour and response to treatment.

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### Quality of life for sarcoma patients

Traditionally the success of cancer treatments, such as chemotherapy, is measured by evaluating how much the tumour changes in size, and the patient's overall survival. How treatments affect the symptoms of disease, the patient's daily functioning and quality of life are rarely measured or incorporated into the findings of large-scale clinical trials. Very little research has been conducted on the impact of changes in quality of life in sarcoma patients, particularly those treated with chemotherapy.

As sarcomas can affect people of all ages there is a need to explore an age-stratified approach to the assessment of quality of life. Age-specific issues are taken into account and enable individualisation of care, ultimately aiming to improve overall patient experience and outcomes.

Dr Eugenie Younger, medical oncology trainee in The Royal Marsden's Sarcoma Unit, has a keen interest in the impact of treatments on sarcoma patients' health-related quality of life. She is currently conducting studies evaluating a number of novel measures of quality of life in sarcoma patients. These include evaluating individual patients' well-being and daily functioning with the aim of providing a more comprehensive assessment for each patient. This work is essential in improving the physical and psychological well-being of sarcoma patients and will provide a benchmark for future studies.



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## Latest studies in sarcoma: genetic risk

### The International Sarcoma Kindred Study (ISKS)

The Royal Marsden's Sarcoma Unit is currently hosting and supporting a number of clinical trials. Recently, an international research project named The International Sarcoma Kindred Study (ISKS), results of which have been published in *Lancet* (August 2016), aimed to shed light on the genetic causation of multiple cancers within families.

Tissue samples and health information were collected from people with and without sarcoma and added to the international registry for researchers to analyse. From this they develop a list of factors that clinicians may look for when assessing the risk of developing sarcoma.

A first-of-its-kind in the field of sarcoma research, the findings from this study will help inform future research.

*“This important study has uncovered mutations occurring in some sarcoma patients that could potentially be targeted by precision treatments – opening up new avenues for treatment that should be investigated in clinical trials. It’s also fascinating that this study has shed light on the inheritance of cancer risk in families more widely, and offers clues to explaining why some families are affected by many different cancer types.”*

Professor Ian Judson, who led the UK arm of the ISKS at The Royal Marsden and The Institute of Cancer Research, our academic partner.

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## Thank you

Thanks to you, The Royal Marsden Cancer Charity is able to support the pioneering work demonstrated above. With your continued support we can invest in further research trials in order to provide better outcomes for sarcoma patients at The Royal Marsden and beyond.