

News Update | December 2023

It has been another positive year for the Foundation with some amazing fundraising events, some generous donations and progress on the various research programmes we are funding. By the end of December, we expect to have raised a total of £800,000 towards our target of £1,000,000.

Much of the funding is ring fence for medical research which is primarily being undertaken at the Sarcoma genomics laboratory at University College London as part of the Edward Showler Foundation Clear Cell Sarcoma (CCS) Research Programme.

To date UCL has collected 60 fresh frozen CCS tissue samples and over 50 FFPE samples. We believe this is the largest collection of CCS tissue samples ever collected and a large number of them have now been whole genome sequenced for DNA, RNA and Methylation analysis.

The results are providing a greater understanding of the genomic landscape of CCS in a way that has never been achieved before. The progress that has been made to date was so clearly explained at the “Meet the Scientist” event we held at University College London in November by Dr Nischalan Pillay. This event was filmed and can be viewed on the Foundation website in the new year.

With the support of a grant from Sarcoma UK we agreed to extend the scope of the programme in March. This will involve further research at the Cancer Institute at UCL, in collaboration with Oxford University, using cutting edge single cell sequencing techniques to understand in detail how Clear Cell Sarcoma cells differ from the normal cells around them.

Because of the success of the project, UCL have been able to leverage the funding the Foundation has provided by obtaining grants from other charities; £120,000 from Sarcoma UK, £50,000 from the Jean Shanks Pathology Society and £250,000 to support a PhD clinical studentship at the University of Basel, Switzerland.

As a result of these additional resources the Programme now employs; 2 PhD students, 2 Clinical Fellows, 1 Post Doctorate Research Fellow and 3 Masters students all working under the excellent leadership of Dr Pillay.

Moving forward the team will be increasing their understanding of CCS by using a range of the most up to date techniques to analyse the data that is being collected.

This will lead on to the drug development phase of the programme, using the highly promising new class of drugs called PROTACs, which can degrade cancer-associated proteins, specifically targeting the differences within tumour cells to minimise toxic side effects. With a greater understanding of the heterogeneity of CSS cells, the team will also be testing existing drugs to see whether they can be repurposed to treat CCS either singularly or in combination.

To assist in this phase of the programme UCL are growing a CCS cell line from a “fresh” tissue sample collected from the National Hospital for Neurology and Neurosurgery, which will act as a surrogate to see how CCS cells might respond to certain therapies.

We feel that, after a little over 2 years, the CCS research programme at UCL, with collaborations in the UK and across the world, has achieved some real momentum and is slightly ahead of where we might have expected to be.

As part of our attempt to reach out to sarcoma patients and their families we circulated a 4-page leaflet to each of the Sarcoma centres in the UK. We have asked that this leaflet be displayed in waiting areas and that clinicians give them to patients. It also provides the contact details to the genomics laboratory at UCL in order to enable clinicians to transfer patient tissue samples, so they can be analysed as part of the programme.

We attended the CTOS conference held in Dublin this November. CTOS is the principal annual worldwide sarcoma conference and we were able to link up with our counterpart CCS charity from the US and to jointly host a CCS patient forum.

A team from UCL also attended CTOS and displayed two scientific posters on CCS at the conference and out of several hundred entries, the poster on the “Single Cell Atlas of CCS,” received the award for the best poster.

Before Ed died, he said that he would like the Foundation to promote better doctor patient communications. Accordingly, we have agreed to part fund a PhD studentship at Cambridge University in doctor patient communications, with an emphasis upon end-of-life care.

The successful application was Arjun Kingdom, a consultant in Palliative Care, a friend of Ed’s and a contemporary of his at Cambridge. Arjun was selected following an interview in March. Arjun will take up his part-time post in the new year, under the guidance of a very strong panel of supervisors drawn from Cambridge University and UCL.

There have been so many fundraising events during the year both here in the UK, on the Gold Coast of Australia and in Ireland. There are too many events to mention each individually but we would like to thank everyone for their hard work in organising fund raisers and for all those who took part. We would also like to thank all those who have so kindly donated to the Foundation during the year. It is so appreciated because your donation allows us to continue to fund research and you can be assured that 100% goes to funding the aims of the Foundation.

Finally, on a sad note, Sharni Ruming died of CCS on the 27th April. Sharni was 30. Her family and friends in both the UK and in Australia have supported Ed’s Foundation in many ways, for which we are very grateful. During the year we have also been in contacted by a number of new patients who have been diagnosed with CCS. It is in memory of Ed, Sian and Sharni and for other CCS patients in the UK and around the world that we must continue to seek to find a treatment and eventually a cure for this disease. It is for this reason that the Foundation exists and this is what continues to motivate all that we seek to do.

John & Ellie

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