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What does the future hold for hairy cell leukaemia?

On Saturday 28 September almost 100 patients, along with their carers, family and friends joined us at our patient and public engagement event 'What does the future hold for hairy cell leukaemia??'

The event was organised and led by [Dr Dima El-Sharkawi](#) ^[9], a Consultant Haematologist at [The Royal Marsden](#) ^[10], and provided an excellent opportunity to find out more about hairy cell leukaemia (HCL), the latest treatment options and advice on nutrition and coping with the emotional impact of living with the condition.

This is our second patient engagement event focusing on rare blood cancers; Dr El-Sharkawi also organised the highly successful **large granular lymphocytic leukaemia** [6] patient event in March 2019.



Figure 1: Attendee feedback from HCL patient engagement event

Around 200 patients ? most commonly males aged 40 to 60 - are diagnosed with HCL in the UK every year. This small patient population means that those with the condition rarely meet others with HCL, and so the event also provided a chance for those affected to meet and share experiences.

What is hairy cell leukaemia (HCL)?

Hairy cell leukaemia (HCL) is a rare, slow-developing cancer of the white blood cells, named for the hair-like protrusions seen on the surface of the cells.

Common symptoms include:

- Breathlessness and being tired (caused by anaemia)
- Prone to infection (caused by neutropenia)
- Prone to bleeding (thrombopenia)
- Enlarged spleen

How is HCL treated?

HCL patients primarily receive chemotherapy ? cladribine or pentostatin ? and generally have a positive, long-term response to this treatment. Alongside chemotherapy, patients may also receive the drug rituximab, which attaches to proteins on the surface of cancerous blood cells so that the immune system can target and kill them.

Clinical trials are underway to uncover further treatment options ? particularly for patients who have relapsed or stopped responding to chemotherapy. A major breakthrough came in 2011 when it was discovered that the majority of HCL patients have a mutation in a gene called BRAF, and that this mutation is driving their cancer. BRAF mutations occur in a number of cancers, most notably melanoma, leading to the development of drugs which specifically target this defect.

Clinical trials have so far shown that BRAF-targeting drugs, such as vemurafenib, dabrafenib and trametinib, could be a valuable option for relapsed HCL patients, however further studies are required to find optimal drug combinations and minimise side-effects.

Research has also led to the development of a new drug Moxetumomab pasudotox, which has shown success in early clinical trials and was **approved by the FDA in 2018** [11].

The drug binds to a protein found specifically on the surface of all hairy cell leukaemia cells and is taken inside the cell where it releases a toxin. **Further clinical trials are currently being designed to confirm these results.** [12]

[Download Dr El-Sharkawi's presentation slides on 'Hairy Cell Leukaemia: The Basics' here](#) [13]

[Download Dr Francesco Forconi's presentation slides on 'The latest developments in HCL'](#) [14]

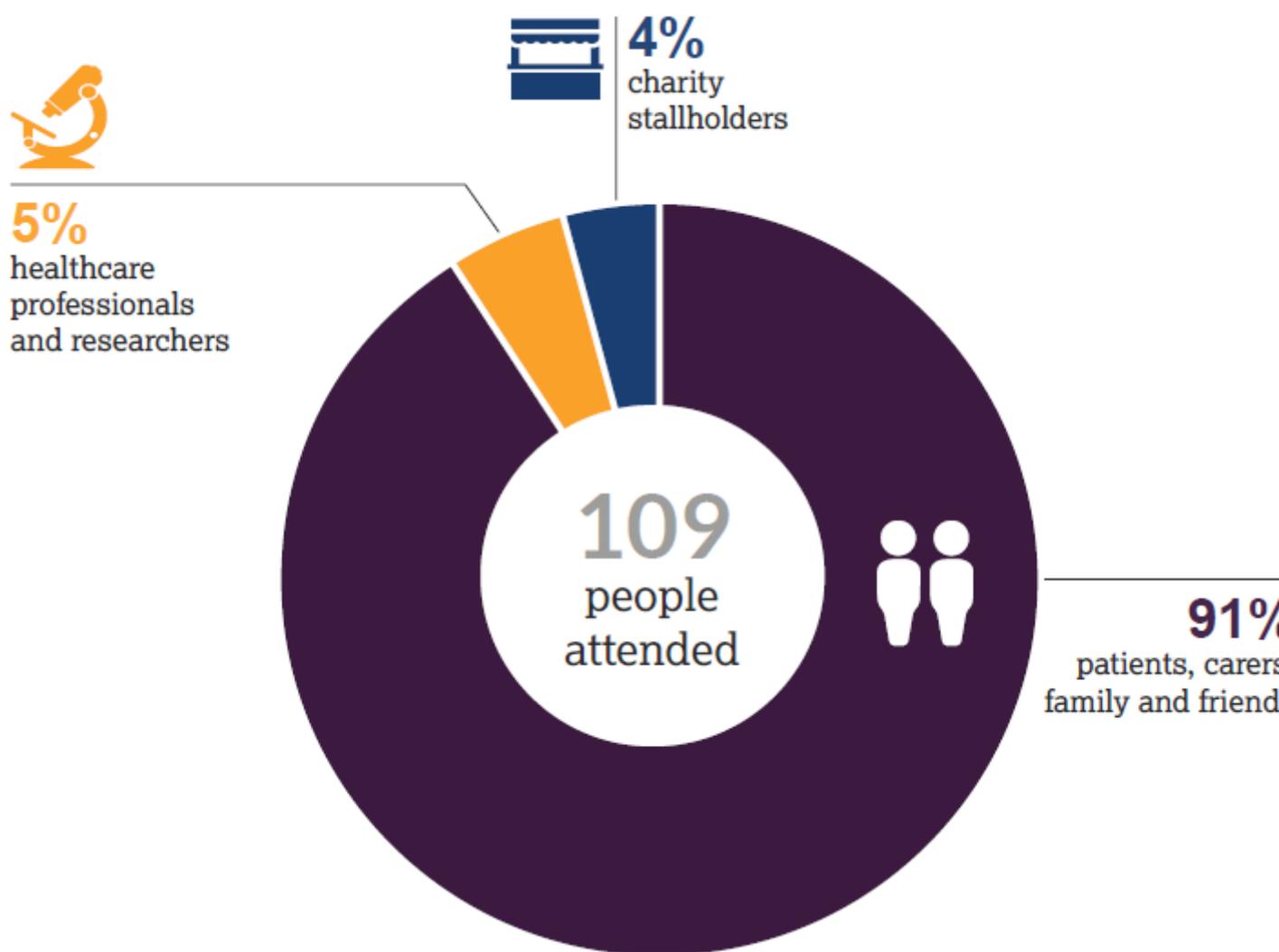


Figure 2: Breakdown of attendees at HCL patient engagement event

The Hairy Cell Leukaemia Patient Registry

The rarity of HCL can make it difficult for researchers to identify common trends across the patient group, such as different sub-types of the condition, complications of treatment and co-morbidities.

Dr Matt Cross, Clinical Research Fellow at The Royal Marsden, discussed the HCL Patient Registry, an initiative led by the [Hairy Cell Leukemia Foundation](#) [15] to gather anonymised data on HCL patients to improve our understanding of the condition and how to treat it.

The Registry will enable doctors, researchers and patients around the world to collaborate and share information, design new clinical trials and ultimately further our understanding of the condition and improve outcomes for patients.

Patients wishing to enrol can email HaemOncGT@rmh.nhs.uk [16]

[Download \[17\] Dr Cross's presentation slides on the Hairy Cell Leukaemia Registry here](#)
[18]

Nutrition

The symptoms of HCL and side effects from treatment may suppress the appetite and therefore impact a patient's ability to maintain their weight and have a nutritious and balanced diet.

Dietician Ciara Tansey discussed strategies that can be used to combat symptoms such as tiredness and fatigue, and side effects including nausea, changes in bowel habit, anxiety and lack of appetite, to help patients eat well throughout treatment and whilst living with the condition. She also discussed the foods that should be avoided by those with a compromised immune system (neutropenic).

[Download \[19\] the presentation slides containing the full version of these strategies, and a list of foods to avoid if immuno-compromised here.](#) [20]

Living with HCL

Patients with HCL often live with the condition for many years and so may experience symptoms and side-effects of treatment long term. Lucy Whiteman, a clinical nurse specialist and key worker in the Haemato-oncology Unit at The Royal Marsden, discussed the practical, family, emotional and spiritual support available to help HCL patients handle the uncertainty of the condition and maintain a normal life.

Clinical Nurse Specialists (CNS) and Key Workers provide guidance in a wide range of areas, from advice about benefits and travel insurance to vaccinations, dietary advice and psychological support. They also provide support in managing symptoms and side effects and are a key point of contact for patients, liaising with medical teams and providing advice over the phone 24 hours a day.

Getting involved in our research

In addition to joining the HCL patient data registry there are several other opportunities for HCL patients wanting to get involved in research at The Royal Marsden.

Please contact patientsinresearch@rmh.nhs.uk [21] to find out more about how you can get involved.

The event was supported by the [Hairy Cell Leukemia Foundation](#) [15] and [The Royal Marsden Cancer Charity](#) [22].

Our research: uncommon cancers [23]

Improving diagnosis, treatment and outcomes of patients with uncommon cancers including cancers of childhood and adolescence

Find out more about our research [23]

Source URL: https://www.cancerbrc.org/HCL_patient_engagement_event

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[1] <https://twitter.com/intent/tweet?url=https%3A%2F%2Fwww.cancerbrc.org%2Fprintpdf%2F436>

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[4] <https://plus.google.com/share?url=https%3A%2F%2Fwww.cancerbrc.org%2Fprintpdf%2F436>

[5] https://shared-d7-royalmarsden-publicne-live.s3-eu-west-1.amazonaws.com/files_brc/s3fs-public/file-attachments/HCL%20patient%20event%20summary%20inforgraphic.pdf

[6] <https://www.cancerbrc.org/news-events/news/what-does-future-hold-large-granular-lymphocytic-leukaemia>

[7] https://www.cancerbrc.org/melanoma_and_urological_cancers_event

[8] https://www.cancerbrc.org/breast_cancer_patient_event

[9] <https://www.royalmarsden.nhs.uk/dr-dima-el-sharkawi>

[10] <https://www.royalmarsden.nhs.uk/>

[11] <https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-moxetumomab-pasudotox-tdfk-hairy-cell-leukemia>

[12] <https://clinicaltrials.gov/ct2/show/NCT01829711>

[13] https://shared-d7-royalmarsden-publicne-live.s3-eu-west-1.amazonaws.com/files_brc/s3fs-public/Dima%20El-Sharkawi%20HCL%202019.pptx

[14] https://shared-d7-royalmarsden-publicne-live.s3-eu-west-1.amazonaws.com/files_brc/s3fs-public/HCL%20RMH%202019_Forconi.pptx

[15] <https://www.hairycellleukemia.org/>

[16] <mailto:HaemOncGT@rmh.nhs.uk>

[17] http://shared-d7-royalmarsden-publicne-live.s3-eu-west-1.amazonaws.com/files_brc/s3fs-public/PDR%20presentation%20Matt%20Cross.pptx

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[21] <mailto:patientsinresearch@rmh.nhs.uk>

[22] <https://www.royalmarsden.org/>

[23] <https://www.cancerbrc.org/our-research/uncommon-cancers>