
THE BONE CANCER CONFERENCE
SATURDAY 28TH SEPTEMBER 2024
THE HILTON, LEEDS
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BONE CANCER RESEARCH TRUST

CONFERENCE PROGRAMME

08:00 – 09:00: Registration and Refreshments
Registration will take place in the lobby near the hotel reception desk (third floor).
Tea and coffee will be available in the Brigante Suite foyer (third floor).

	Third Floor	Fourth Floor		
	Brigante Main Presentation Room	**Thoresby** Childcare	**Magnum** Quiet Room	**Boardroom** Interview Filming
Session 1: **09:00 – 10:30**	**09:00 – 09:10** Welcome & overview of the day **Charlene Young *(osteosarcoma patient & BCRT Trustee)*** Introducing a new role at BCRT **Silvia Kraft *(Policy & Awareness Officer)***	**Childcare**	**Quiet Room**	**Interview** **Filming**
	1A: 09:10 – 09:50 *** Keynote Speaker 1 *** The #hellomynameis Story – 'Through Adversity comes Legacy' **Chris Pointon**			
	1B: 09:50 – 10:05 Personalising the pathway... Research activities at the Oxford Spinal Sarcoma Service **Gerard Mawhinney**			
	1C: 10:05 – 10:20 Sophie's remission life **Sophie Hartley**			
	1D: 10:20 – 10:30 A message from our main sponsor - JMW Solicitors **Mark Havenhand**			

10:30 – 11:15: Morning Break
Refreshments will be served in the Brigante Suite foyer

Session 2: **11:15 – 12:30**	**2A: 11:15 – 11:30** The start of Chloë's journey **Joanne Venton**	**Childcare**	**Quiet Room**	**Interview** **Filming**
	2B: 11:30 – 11:45 Personalisation of chemotherapy dosing to maximise response & minimise toxicity through an understanding of drug exposure **Gareth Veal**			

	2C: 11:45 – 12:00 BritE StAr - British Early diagnosis in Sarcoma Audit **Sophie Howles**	**Childcare**	**Quiet Room**	**Interview Filming**
	2D: 12:00 – 12:15 A personal journey – the evolution of PPI **Linda Galbraith**			
	2E: 12:15 – 12:30 LifeArc Childhood Cancer Translational Challenge **Natasha Ratcliffe**			
12:30 – 14:00: Lunch Lunch will be served in the City 3 Restaurant				
Session 3: **14:00 – 15:15**	**3A: 14:00 – 14:15** My journey with sacral GCT of the bone **Anne-Marie Creamer** *(pre-recorded)*	**Childcare**	**Quiet Room**	**Interview Filming**
	3B: 14:15 – 14:30 CAR T cell strategies for solid cancers of childhood **Martin Pule**			
	3C: 14:30 – 14:45 Improving CAR T cell therapy for osteosarcoma **Carmen Rodriguez**			
	3D: 14:45 – 15:00 Life after bone cancer **Lauren Fishman**			
	3E: 15:00 – 15:15 Cancer Support UK Introduction **Emma Kennedy-Cox**			
15:15 – 16:00: Afternoon Break Refreshments will be served in the Brigante Suite foyer				
Session 4: **16:00 – 17:00**	**4A: 16:00 – 16:15** Birmingham Orthopaedic Oncology Meeting (BOOM): Reaching consensus in chondrosarcoma **Lee Jeys** *(pre-recorded)*	**Childcare**	**Quiet Room**	**Interview Filming**
	4B: 16:15 – 16:30 Modifying methotrexate for osteosarcoma - next steps? **Hannah Spencer**			

	4C: 16:30 – 16:50 *** Keynote Speaker 2 *** Bethany's journey with osteosarcoma **Bethany Barnes**	**Childcare**	**Quiet Room**	**Interview Filming**
	16:50 – 17:00 Closing remarks **Vina Hajari *(Support Manager)* and Ruby Campbell *(Support Officer)***			

19:30 – 22:30: Evening Social
For those of you attending the evening social, please make your way back to the Brigante Suite at 19:30.

SUMMARY OF PRESENTATIONS

Welcome & overview of the day: **Charlene Young** ***(osteosarcoma patient & BCRT Trustee)***

Introducing a new role at BCRT: **Silvia Kraft** ***(Policy & Awareness Officer)***

SESSION 1:

A. ***Keynote Speaker 1***
The #hellomynameis Story – 'Through Adversity comes Legacy' **– Chris Pointon**: Chris is the widower of Dr Kate Granger MBE and a global campaign ambassador for the #hellomynameis campaign. He will share the story of how the campaign came about and how it has evolved over the years, along with a personal journey of his and Kate's life.

B. ***Personalising the pathway... Research activities at the Oxford Spinal Sarcoma Service*** **– Gerard Mawhinney:** Gerard is a Consultant Nurse in Spinal Sarcoma / Surgery at Oxford University Hospitals NHS Trust and BCRT 2024 'Clinician of the Year'. Alongside his clinical work, Gerard is a 3yr PhD student at the University of Oxford, where his research explores how precision oncology is implemented and experienced by people living with primary tumours of the brain and spine.

C. ***Sophie's remission life*** **– Sophie Hartley*:*** Sophie is in long-term remission from Ewing sarcoma. After having Ewing99 protocol when she was diagnosed in 2005, followed by a decade of surgeries, Sophie has gone on to use her lived experience in charity work. She shares how she is committed to living her best remission life.

D. ***A message from our main sponsor, JMW Solicitors –*** **Mark Havenhand:** JMW is a full-service law firm offering expertise across every area of the law to both businesses and individuals. We're delighted to welcome JMW back as our main sponsor for the third year.

SESSION 2:

A. ***The start of Chloë's journey*** **– Joanne Venton:** Joanne's daughter Chloë passed away from Ewing sarcoma in 2020. Joanne is sharing their journey and experience in her own words and pictures, from Chloë's symptoms through to diagnosis and then treatment.

B. ***Personalisation of chemotherapy dosing to maximise response & minimise toxicity through an understanding of drug exposure*** **– Gareth Veal:** Gareth Veal is Professor of Cancer Pharmacology at Newcastle University. He has been working in cancer research for over 25 years, since returning to the UK from a postdoctoral post in the US,and is the author of well over 100 scientific publications in peer reviewed journals. He leads the Newcastle Cancer Centre Pharmacology Group, a research team with vast experience in running clinical pharmacology trials and an award winning national therapeutic drug monitoring service. He has been the lead applicant on grant applications awarded >£5 million in the past 10 years, including grants from Cancer Research UK, Innovate UK, the NIHR, the Bone Cancer Research Trust and the Little Princess Trust.

C. ***BritE StAr - British Early diagnosis in Sarcoma Audit –*** **Sophie Howles:** Sophie is an orthopaedic registrar at the Royal Orthopaedic Hospital in Birmingham and has been working with a team from across the UK on a national collaborative project with a focus on early diagnosis in sarcoma. Sophie and the team are aware of the huge impact that early diagnosis has on outcomes for patients with sarcoma, and hope that by identifying patterns in the way that sarcomas are diagnosed, they will be able to improve the pathways to diagnosis and treatment for patients in the future.

D. ***A personal journey – the evolution of Patient & Public Involvement (PPI)*** **– Linda Galbraith:** Linda started her career as an NHS manager, before moving to social work management, then becoming a director of an arts charity. From here, she set up a management consultancy, firstly in the arts, then in the third sector, but had to stop work as a result of developing a sarcoma and complications post-surgery, which resulted in a suppressed immune system. She joined an ethics committee six years ago, and was approached to join the RadNet Glasgow Committee, where she is PPI Lead and sits on the strategic and funding committee. She is also Chair of ACED US/UK PPI group and will be presenting a paper on the future of ACED PPI at Stanford next month, as well as being Co-Chair PPI Group Scottish Cancer Centre and Co-Investigator for Headspace project in Brazil. Linda will share her wealth of lived experience as both a primary bone cancer patient and a PPI advocate.

E. ***LifeArc Childhood Cancer Translational Challenge –*** **Natasha Ratcliffe:** Dr Natasha Ratcliffe is a specialist in patient and public involvement in research and joined LifeArc in 2024. Her work is focused on supporting the development of effective, equitable, and sustainable partnerships with patients and communities to help improve and maximise the impact of research. Natashas leads LifeArc's strategy for patient engagement and supports colleagues across LifeArc to involve patients and communities in our work. Natasha has extensive experience working with the charity sector, academia and industry, and previously led the Research Involvement programme at Parkinson's UK. Natasha is also a visiting lecturer at King's College London, working with the Centre for Pharmaceutical Medicine Research to support research and education on patient engagement in medicines development.

SESSION 3:

A. ***My journey with sacral GCT of the bone*** **– Anne-Marie Creamer:** Anne-Marie was diagnosed with a sacral Giant Cell Tumour of the Bone when she was 51. She is also an artist, and Senior Lecturer and researcher at the University of the Arts, London. She recounts her journey and highlights the importance of knowledge and advocacy, narrative and illness, the tricky navigation of the language around rare intermediate tumours, the

singular nature of the relationship between doctors and patients, and ultimately coming to terms with living with a tumour and its impact on her life in the arts.

B. ***CAR T cell strategies for solid cancers of childhood*** **– Martin Pule:** Martin Pule is Clinical Senior Lecturer in the Dept. of Haematology at UCL Cancer Institute and Honorary Consultant in Haematology at University College London Hospital. He holds a Bachelor of Medicine and Bachelor of Surgery from University College Dublin and is a Fellow of the Royal College of Pathologists. His research is focused on many aspects of genetic engineering of T-cells for cancer treatment, with a particular focus on CARs. He entered the T-cell engineering field in 2001 as a travelling Fulbright Scholar at the Center for Cell and Gene Therapy at Baylor College of Medicine, Houston. Here, Martin was the first to describe third generation forms of CARs and described one of the first clinical studies of CARs, which showed efficacy in a solid cancer. Martin established and is Director of the UCL Chimeric Antigen Receptor (CAR) programme. He is founder and chief scientist officer of Autolus Therapeutics.

C. ***Improving CAR T cell therapy for osteosarcoma*** **– Carmen Rodriguez:** Carmen is a PhD student at the UCL Cancer Institute, funded by the Bone Cancer Research Trust, conducting cutting-edge research on CAR-T cell immunotherapy for osteosarcoma. Her work aims to enhance the therapeutic potential of engineered T cells to target and eliminate osteosarcoma cells, with the goal of developing novel cancer treatments to improve patient outcomes.

D. ***Life after bone cancer*** **– Lauren Fishman:** Lauren shares her experience of being diagnosed with Ewing sarcoma when she was a teenager. 5 years post-treatment, Lauren is determined to raise awareness of Ewing sarcoma and continue to reach her life goals and ambitions.

E. ***Cancer Support UK Introduction*** **– Emma Kennedy-Cox:** Cancer Support UK is a charity that helps those affected by cancer by providing emotional support through their cancer coaching events and practical support by providing free cancer kits for adults and children undergoing treatment.

SESSION 4:

A. ***Birmingham Orthopaedic Oncology Meeting (BOOM): Reaching consensus in chondrosarcoma*** **– Lee Jeys:** Professor Lee Jeys is a Consultant Orthopaedic Surgeon at the Royal Orthopaedic Hospital NHS Trust, where he performs around 400 operations per year including knee surgery, knee replacement, and revision knee replacements. Professor Jeys also specialises in the treatment of bone tumours and soft tissue tumours. He has published over 50 scientific papers in the world's most important orthopaedic journals and has written three chapters in textbooks about surgery. He regularly lectures around the world on joint replacement and tumour surgery.

B. ***Modifying methotrexate for osteosarcoma - next steps?*** **– Hannah Spencer:** After gaining a BSc in Clinical Sciences and MSc in Biomedical Sciences from the University of Bradford, Hannah took a Research Assistant position working on the synthesis of metal based anticancer drugs alongside Dr Rianne Lord (2017-18). She gained her PhD in 2022 under the supervision of Professor Robert Falconer, Professor Paul Loadman and Dr Steven Shnyder; funded by BCRT. In her Postdoctoral position, also funded by BCRT, Hannah is continuing to work towards developing kinder treatments for OS.

C. ***Keynote Speaker 2***
Bethany's journey with osteosarcoma **– Bethany Barnes:** Bethany Barnes is 27 years old and was misdiagnosed while serving in the Royal Navy for nearly 5 years. She will be talking about her journey through the military and dealing with osteosarcoma and a sarcoma relapse while also becoming a mum.

Closing Remarks: **Vina Hajari** ***(Support Manager)***

GLOSSARY OF TERMS

A

Adjuvant: treatment applied after an initial form of treatment. For example, adjuvant chemotherapy is administered after surgery.
Alopecia: the medical name for hair loss.
Amputation: removal of a limb due to a trauma or disease.
Anaemia: a lower than normal level of red blood cells in the blood; this can leave you feeling worn out or dizzy.
Anaesthetic: medicine used during tests and surgical procedures to numb certain areas of the body or induce sleep to prevent pain or discomfort.
Analgesic: the medical name for a painkiller.
Antiemetics: drugs that stop patients from feeling nauseous or being sick.
Asymptomatic: a condition or disease which produces no symptoms.
Autograft: replacing tissue from one part of a patient's body using tissue from another area of their body.

B

Benign: a mass of cells that is not cancerous. These tumours grow in one place and do not spread.
Biobank: a collection of anonymised patient samples and clinical data stored for use in research.
Biopsy: a small sample of tissue that is taken so a doctor, known as a pathologist, can look closely at the cells making up the tumour and run tests on the sample.

C

Cancer: a disease caused by abnormal and uncontrolled growth and division of cells.
Cannula: a flexible tube inserted into a blood vessel in the lower arm or hand to give medicine or an anaesthetic.
Central Line: a long, flexible, tube that goes into the central blood vessel in the chest. This is used to give medicines, fluid or to take blood from a patient.
Chemotherapy: A treatment for cancer that uses one or more medicines to kill cancer cells.
Chemoresistant: when a certain cancer type, or specific patients' tumour, does not respond to chemotherapy.
Cisplatin: a chemotherapy drug that is given to primary bone cancer patients. Cisplatin works by binding (or sticking) to DNA to cause the cell to die.
Clinical Trials: Used to test how well new medicines or treatments work in people.
Curettage: a method of surgery which removes the tumour by scraping or scooping the cancerous cells away.
Cyclophosphamide: a chemotherapy drug that is given to primary bone cancer patients. This drug is known as an 'alkylating agent' and it slows down the growth of cancer cells.
Cytotoxic: drugs that are toxic to cancer cells and cause them to die.

D

Dexamethasone: a steroid drug which decreases inflammation. Dexamethasone may be used to manage some of the side effects caused by cancer treatment.
Diagnostic: the techniques and procedures used to diagnose a disease.
DNA: stands for deoxyribonucleic acid. This is present in all living organisms and carries the genetic material of a cell.
Doxorubicin: A chemotherapy medicine used to treat primary bone cancer. Doxorubicin is a red liquid that is given into a vein by infusion. It is a type of medicine called an 'anti-tumour antibiotic'. It affects the cancer cell's DNA when it is getting ready to divide.

E

Eligibility criteria: certain requirements that an individual must meet in order to take part in a clinical trial.
Endoprosthesis: an artificial implant used to replace part of the body that is missing; 'endo' means 'inside'.
Enneking System: a staging system of musculoskeletal tumours to classify tumours in order to determine the best way to treat them.
Etoposide: A chemotherapy medicine used to treat primary bone cancer. Etoposide is a white powder, which is then made into a colourless liquid. It is usually given into a vein by infusion. It is a 'topoisomerase II poison' and stops DNA from fixing itself, this kills the cancer cells.

F

Fatigue: the medical definition for extreme tiredness caused by a disease.
Femur: the bone in the upper leg, also known as the thighbone.
Fibula: the smaller, outer, bone of the leg between the knee and the ankle, also referred to as the calf bone.
Follow-up: care given after finishing treatment to check for medical issues that may arise months or years after treatment has finished.

G

G-CSF: short for granulocyte colony stimulating factor. A growth factor that stimulates the bone marrow to produce white blood cells.
Genes: Found inside each cell. A gene is a set of instructions that tell the cell what type of cell it is, when to divide and when to die. Genes are made up of DNA.

H

Hickman Line: a long, flexible, tube that goes into a vein in the chest. This is used to give medicines, fluid or to take blood from a patient.
High-Dose Chemotherapy: cancer treatment using very high doses of chemotherapy drugs to kill cancer cells.
Holistic Needs Assessment (HNA): An assessment and discussion you may have with someone from your healthcare team. Together, you talk through your needs and concerns. You then agree on a plan for your care and support needs.
Humerus: the bone of the upper arm which forms joints at the shoulder and the elbow.

I

Ifosfamide: A chemotherapy medicine used to treat primary bone cancer. Ifosfamide is an 'alkylating agent'. It works by damaging DNA so it cannot copy itself. This makes it difficult for the cells to divide.
Incidence: the rate at which a disease is occurring, or the frequency of a disease.
Infertile (infertility): the inability to have children. Infertility can be a side effect of cancer treatment.
Intensity-Modulated Radiotherapy (IMRT): an advanced form of radiotherapy that uses computerised planning to deliver the radiation to the tumour with little effect to surrounding tissues.
Intermittent pain: a term used to describe pain which comes and goes.
Intravenous (IV): simply means 'within the veins' and this is one of the best ways to administer treatment and fluids as it is a quick route of delivery to the body.

L

Late effects: problems that patients may develop after cancer treatment, these can occur months or even years after treatment has finished.
Lesion: an area of a tissue that has suffered damage; this may be from injury or disease and may range from a wound to a tumour.
Limb-Sparing Surgery: Surgery to remove a tumour from an arm or leg (limb). It is used instead of amputation where possible and aims to allow the limb to work well after surgery.
Liver Function Tests (LFT's): a blood test which gives information on the functioning of a patient's liver. This is a useful test for determining the body's reaction to treatment.
Localised Cancer: cancer that has not spread to other areas of the body.

M

Malignant: tumours that are cancerous and have the ability to spread.
Metastasis: the spread of cancer to another area of the body to form a secondary tumour. Primary bone cancer can spread to the lungs or to other bones.
Methotrexate: a chemotherapy drug that is given to primary bone cancer patients to slow down the growth of cancer cells by interfering with the production of the cell's DNA.
Metoclopramide (Maxolon): a drug used to treat nausea and vomiting, which may be a side effect of chemotherapy.
Mifamurtide (Mepact): A treatment for osteosarcoma patients between 2 and 30 years, it can be given to patients after surgery alongside chemotherapy.
Multi-Disciplinary Team (MDT): a team made up of various healthcare professionals with differing skills and areas of expertise. An MDT work together to ensure each patient receives the best possible treatment plan.

N

Nausea: the feeling of sickness and needing to vomit.
Neo-Adjuvant: treatment carried out before the main treatment procedure. For example, neo-adjuvant chemotherapy aims to shrink the tumour to allow an easier surgical procedure to follow.
Neutropenia: a low count of white blood cells, known as neutrophils, in the blood. This is often caused by chemotherapy and affects the immune system, increasing a patient's risk of infection.

O

Ondansetron: a drug used to treat or prevent nausea and vomiting associated with cancer treatment.
Orthopaedic: the branch of medicine specialising in the bone and muscles.
Orthotist: a specialist who provides aids for people with nerve, muscle or bone disorders. These aids include special footwear.
Osteoblast: cells which specialise in making bone. They work alongside osteoclasts to constantly remodel and reshape the bone.
Osteoclast: cells which breakdown the bone. They work alongside osteoblasts to constantly remodel and reshape the bone.
Outcome: the result of a disease that directly affect the length or quality of a patient's life.
Outpatient: attending hospital for treatment without needing to stay overnight. Some radiotherapy or chemotherapy may be given in outpatients.

P

Paediatrician: a doctor who specialises in treating children.
Palliative: treatment used to help support patients and to manage or relieve their symptoms to improve their quality of life.
PEG (Percutaneous Endoscopic Gastrostomy): used to get nutrients and fluids directly into a patient's stomach if they are unable to eat or swallow.
PICC Line: a long, flexible, tube that goes into a vein in the arm, leg or neck. This is used to give medicines, fluid or to take blood from a patient.
Portacath: a thin, flexible, tube inserted into a blood vessel in the chest then connected to a small box which lies under the skin. This small box is used to give medicines, fluid or to take blood from a patient.

Primary tumour site: the site where the cancer originated and developed.
Prognosis: the long-term outlook of a disease in terms of survival and recovery.
Promethazine: a drug used to treat allergic reactions or act as a sedative to induce calm and sleepiness.
Prosthetic: an artificial limb designed to replace a missing part of the body.
Prosthetist: a specialist who designs and creates artificial limbs for individuals.
Proton Beam Therapy: an advanced form of radiotherapy. Unlike conventional radiotherapy, proton beam therapy stops once it "hits" the cancerous cells; resulting in much less damage to surrounding tissues.

R

Radiotherapy: a form of cancer treatment that uses high-energy x-rays to damage and destroy cancer cells.
Radius: one of two bones making up the lower arm. It runs from the thumb to the elbow.
Reconstruction: surgery carried out following the removal of the tumour to restore the functioning and appearance of the affected area of the body.
Recurrence or Relapse: cancer returning at a later date after treatment has finished.
Referral: the transfer of a patient's care from one medical professional to another.
Regimen: a plan of the medicines that a patient will have. The regimen will inform all carers of the treatment plan, the dose and how long and how often it will be given for.
Rehabilitation (Rehab): a specialised form of care that is carried out after treatment. Rehab, which may include physiotherapy and/or occupational therapy, allows the patient to return to normal life and regain their strength and independence.
Remission: when the signs or symptoms of cancer have disappeared, a patient is in remission.

S

Sarcoma: cancer that forms in the connective tissues of the body; such as the bone, muscles, nerves or fat. Primary bone cancer is also known as bone sarcoma.
Second opinion: getting the view of a medical professional who has not previously been involved in a patient's care.
Side effects: undesirable effects to healthy areas of the body caused by treatment.
Stem cell: cells capable of developing into many different types of cells; they act as a repair system to replace cells.
Stem cell harvest: a procedure used to collect stem cells from a patient in order to store them and return them at a later date. This is carried out so that any blood cells destroyed by chemotherapy can be replaced with these stem cells during a stem cell transplant.

T

Terminal: a word used to describe a disease, such as cancer, which cannot be cured.
Tibia: the larger, inner, bone of the leg between the knee and the ankle; also referred to as the shin bone.
Tissue: consists of specialised cells which form areas of the body to carry out a specific function.
Topotecan: a chemotherapy drug that is given to primary bone cancer patients. This drug works by stopping an enzyme known as Topoisomerase I from working, which leads to damaged DNA and the cancer cell being destroyed.
Treatment cycles: a cycle includes the treatment time, which may be 3-4 days plus a rest period for the body to recover.
Tumour: is a swelling or lump caused by the abnormal growth and mass of cells. Tumours can be benign (non-cancerous) or malignant (cancerous).
Tumour grade: a way of classifying the tumour. It assesses how abnormal the cells of the tumour appear; how different the tumour is to a healthy tissue and how quickly the cells are dividing. High grade tumours are often more aggressive.
Tumour marker: a substance produced by a tumour which can be found in the blood and help doctors to understand how the tumour is behaving.
Tumour stage: a way of describing how big the tumour is and whether or not it has spread to neighbouring tissues or other areas of the body.

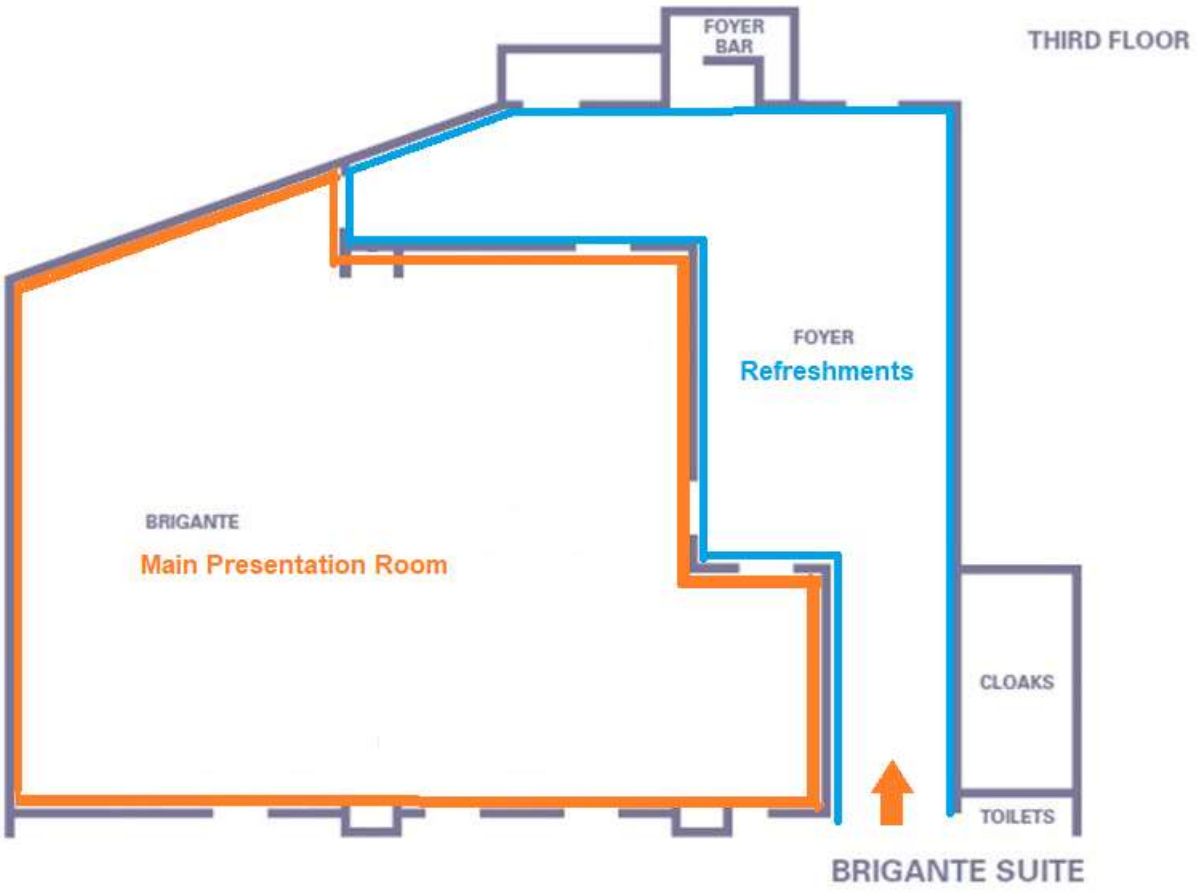
U

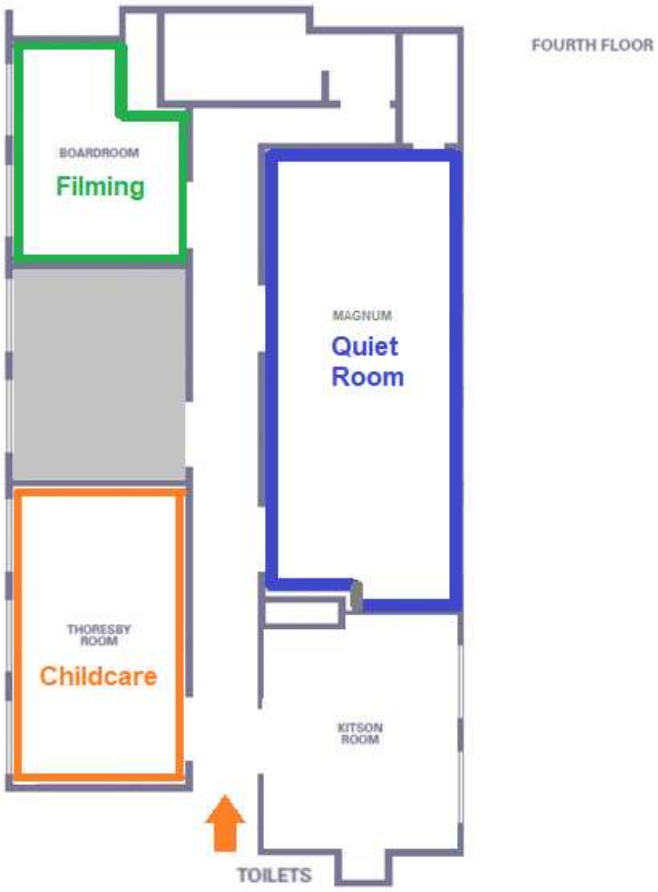
Us & Es (short for urea and electrolytes): a type of blood test to examine the levels of waste products in the blood. This can give clues as to how well the kidneys are working.

W

White blood cells: blood cells which are part of the immune system and therefore help the body to fight off infections and disease.

HOTEL FLOOR PLAN





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ABOUT THE BONE CANCER CONFERENCE 2024

We are so pleased that you are joining us at The Bone Cancer Conference 2024. Whether you're a patient, family member, supporter, researcher, or medical professional, we hope you have an informative and inspiring day.

Our conference is all about bringing our community together in a forum like no other. The day should provide you with the time and space to discuss issues that are important to you. If you have any questions throughout the day or would like to speak to one of our team, please just let us know. You will find the Bone Cancer Research Trust staff in orange BCRT t-shirts and blue “staff” lanyards.

You, our community, are so important to us and are crucial to our ultimate aim of finding a cure for primary bone cancer. We hope you have a thoroughly enjoyable day and thank you, once again, for coming to The Bone Cancer Conference 2024.

SPONSOR

Sponsoring The Bone Cancer Conference helps us to raise awareness of primary bone cancer and ensure patients and families get the support that they need. We would like to thank our conference sponsor, **JMW Solicitors**, for supporting this event over the last three years.