



2023 Sarcoma Summit

Friday 22 September, 10am to 4:30pm

Kerry Packer Education Centre Auditorium,
Royal Prince Alfred Hospital



Sydney
Local Health District



Acknowledgement of Country

Sydney Local Health District acknowledges that we are living and working on Aboriginal land. We recognise the strength, resilience and capacity of Aboriginal people on this land. We would like to acknowledge all of the traditional owners of the land and pay respect to Aboriginal Elders past and present.

Our District acknowledges *Gadigal*, *Wangal* and *Bediagal* as the three clans within the boundaries of the Sydney Local Health District. There are about 29 clan groups within the Sydney metropolitan area, referred to collectively as the great *Eora Nation*. *Always was and always will be Aboriginal Land*.

We want to build strong systems to have the healthiest Aboriginal community in Australia.

Together under the Sydney Metropolitan Partnership Agreement, including the Aboriginal Medical Service Redfern and in collaboration with the Metropolitan Local Aboriginal Land Council, Sydney Local Health District is committed to achieving equality to improve self-determination and lifestyle choices for our Aboriginal community.

Ngurang Dali Mana Burudi – A Place to Get Better

Ngurang Dali Mana Burudi — a place to get better, is a view of our whole community including health services, Aboriginal communities, families, individuals and organisations working in partnership.

Our story

Sydney Local Health District's Aboriginal Health story was created by the District's Aboriginal Health staff.

The map in the centre represents the boundaries of Sydney Local Health District. The blue lines on the map are the Parramatta River to the north and the Cooks River to the south which are two of the traditional boundaries.

The *Gadigal*, *Wangal* and *Bediagal* are the three clans within the boundaries of Sydney Local Health District. They are three of the twenty-nine clans of the great *Eora Nation*. The centre circle represents a pathway from the meeting place for Aboriginal people to gain better access to healthcare.

The Goanna or *Wirriga*

One of Australia's largest lizards, the goanna is found in the bush surrounding Sydney.

The Whale or *Gawura*

From June to October pods of humpback whales migrate along the eastern coastline of Australia to warmer northern waters, stopping off at Watsons Bay the traditional home of the Gadigal people.

The Eel or *Burra*

Short-finned freshwater eels and grey Moray eels were once plentiful in the Parramatta River inland fresh water lagoons.

Source: Sydney Language Dictionary



Artwork

Ngurang Dali Mana Burudi — a place to get better

The map was created by our Aboriginal Health staff telling the story of a cultural pathway for our community to gain better access to healthcare.

Artwork by Aboriginal artist Lee Hampton utilising our story.

Program

Time	Activity
9:55am–10am	Introduction Julie McCrossin AM
10am–10:05am	Welcome to Country Uncle Allen Madden
10:05am–10:10am	Official Welcome Dr Teresa Anderson AM, Chief Executive, Sydney Local Health District
10:10am–10:40am	What we can do now in Sarcoma Surgery, followed by Q&A Dr Richard Boyle, Orthopaedic Surgeon, Director RPA Bone and Soft Tissue Sarcoma Unit
10:40am–10:50am	Changing the narrative about living with a disability James Parr, Osteosarcoma survivor, triathlete, model, disability advocate, writer, proud Wiradjuri boy
10:50am–11:20am	Panel Discussion: What is working well? Dr Maurice Guzman, Orthopaedic Surgeon, RPA Bone and Soft Tissue Sarcoma Unit Associate Professor Wayne Nicholls, Director, Oncology Services Group Queensland Children’s Hospital; Clinical Director, Ian Frazer Centre for Children’s Immunotherapy Research, University of Queensland Neil Gibson, Father to Jack (dec) osteosarcoma; Director of the Jack Gibson Sarcoma Patient & Family Support Programme Rebecca Minty, Mother of Zac (forever 11) rhabdomyosarcoma; Founder Bricks & Smiles
11:20am–11:50am	Panel Discussion: The challenges and the hope Dr Daniel Franks, Orthopaedic Surgeon, RPA Bone and Soft Tissue Sarcoma Unit Neema Rajak, Principal carer to brother Nikesh living with osteosarcoma Kaela Graham-Bowman, Sarcoma patient and nurse Associate Professor Antoinette Anazodo OAM, Paediatric and Adolescent Oncologist and Clinician Academic, University of New South Wales
11:50am–12:05pm	Questions with Julie McCrossin AM
12:05pm–12:15pm	Prospectus and Website Launch Dr Teresa Anderson AM, Chief Executive Dr Richard Boyle, Orthopaedic Surgeon, Director RPA Bone and Soft Tissue Sarcoma Unit
12:15–12:45pm	Lunch
1pm–2pm	Ground Rounds: Can a surgeon cure osteoporosis? Associate Professor Rooshdiya Karim, Staff Specialist, Department of Tissue Pathology and Diagnostic Oncology, NSW Health Pathology Dr Emily Davidson, Radiologist, Department of Radiology, RPA Dr Isobelle Smith, Endocrine Advanced Trainee, RPA Dr Aneesh Dave, Registrar, Orthopaedic Department, RPA

Time	Activity
2pm–2:20pm	Afternoon tea
2:20pm–2:30pm	Psycho-Social Support from diagnosis through treatment and beyond Louise Hird, Clinical Psychologist, Psychoanalyst, Child and Adolescent Therapist/Supervisor/ Founder - CRBF psychological & emotional support programme
2:30pm–2:40pm	What chemotherapy looks like in the future Professor Peter Grimison, Medical Oncologist RPA and Chris O’Brien Lifehouse
2:40pm–2:50pm	Clinical practice guidelines for management of sarcoma and evidence for treatment at specialised Sarcoma Centres Associate Professor Angela Hong, Radiation Oncologist, RPA and Chris O’Brien Lifehouse
2:50pm–3pm	What genomics will look like in the future Professor David Thomas, Director, Centre for Molecular Oncology, University of New South Wales; Chief Executive Officer, Omico: Australia Genomic Cancer Medicine Centre; Laboratory Head, Genomic Cancer Medicine, Garvan Institute of Medical Research
3pm–3:15pm	Video: English Channel Swim Dr Chris Watson, Registrar, Ophthalmology
3:15pm–3:20pm	The Sony Foundation - supporting young sarcoma patients Emma Pechey, General Manager Sony Foundation Australia
3:20pm–3:30pm	Launch of the new Sarcoma Unit Dr Richard Boyle, Orthopaedic Surgeon, Director RPA Bone and Soft Tissue Sarcoma Unit Dr Owen Hutchings, Clinical Director, RPA Virtual Hospital
3:30pm–4:10pm	Panel Discussion: Caring for the carers and the clinicians Mitchell Rice-Brading, Bachelor of Psychology (Honours) University of Sydney; CRBF Patient Advocate (video message) Dr Richard Boyle, Orthopaedic Surgeon, Director RPA Bone and Soft Tissue Sarcoma Unit Louise Hird, Clinical Psychologist, Psychoanalyst, Child and Adolescent Therapist/Supervisor/ Founder - CRBF psychological & emotional support programme Mandy Basson, Mother of Abbie (dec) Ewing sarcoma; Executive Director Sock it to Sarcoma! Karen Atkins, Mother/carers to Imogen (Osteosarcoma survivor), Paediatric and Adult Palliative Spiritual Care Practitioner Dr Vivek Bhadri, Paediatric and Adolescent Medical Oncologist, Chris O’Brien Lifehouse; Adolescent Medical Oncologist, Westmead Hospital and RPA
4:10pm–4:25pm	Questions with Julie McCrossin AM
4:25pm–4:30pm	Next steps Dr Teresa Anderson AM, Chief Executive Sydney Local Health District
4:30pm–6pm	Cocktail party

Biographies

Dr Teresa Anderson AM Chief Executive, Sydney Local Health District

Dr Teresa Anderson has worked in the NSW public health system for more than 40 years. She is currently the Chief Executive of Sydney Local Health District, providing services 740,000 people living within Sydney and more than 1 million that come into the District each day to work, study and visit.

Dr Anderson has extensive experience as a clinician, manager and health service leader and has a well established reputation for implementing strategies to foster innovation and best practice.

Dr Anderson is focussed on supporting collaboration and building partnerships to provide excellent health care and is widely acknowledged for supporting and mentoring her staff in fostering new ideas and drive efficiencies and best practice.

This was recognised with the District’s eMR and eMeds program winning the Minister of Heath’s Award for Innovation in 2015 and the Prime Minister’s 2016 Silver Award for Excellence in Public Sector Management.

She continues to develop programs and services to support and improve the health and wellbeing of all people in the community.

In the 2018 Queens Birthday Honours, Dr Anderson was made a Member of the Order of Australia for her service to community health and to public administration in New South Wales as a clinician, manager and health service executive.

To also recognise Dr Anderson’s outstanding service to the community and to public administration she was awarded a IPAA National Fellowship.

Julie McCrossin AM Emcee

Julie McCrossin gets people talking. After 20 years as a presenter with ABC Radio National, ABC TV and Network Ten, she is now a freelance broadcaster, podcaster and MC.

Julie was treated for stage four, HPV-related oropharyngeal cancer (tonsils, tongue and throat) in 2013. Julie is an Ambassador for Targeting Cancer and TROG Cancer Research. She is a member of the advocacy group, Cancer Voices SA. Julie hosts the

podcast series, The Thing About Cancer and The Thing About Advanced Cancer for Cancer Council NSW.

Julie has co-produced and presented a range of educational videos in partnership with cancer clinicians and advocates. Julie’s recent video series include Talking To Doctors for Cancer Voices SA; the Head and Neck Cancer Video Series 2020/2021 with St Vincent’s Hospital Sydney, St Vincent’s Private Hospital and the Kinghorn Cancer Centre; and How Can We Improve the Patient and Family Experience of Radiation Therapy? in 2020/2021 with SAHMRI, the South Australian Health and Medical Research Institute. Julie has qualifications in the arts, education and law.

In 2019, Julie was awarded a Member of the Order of Australia for significant service to the community, particularly through LGBTIQ advocacy roles and to the broadcast media.

Dr Richard Boyle Orthopaedic Surgeon, Director RPA Bone and Soft Tissue Sarcoma Unit

Dr Richard Boyle is a senior consultant Orthopaedic Surgeon who graduated with Honours in Medicine from the University of NSW. He completed his Orthopaedic training in Sydney and undertook further subspecialist training at RPA and internationally in Toronto, Canada, Basel, Switzerland, and Vienna, Austria.

Dr Boyle is one of only a few Orthopaedic Surgeons in NSW with expertise in the surgical management of patients with bone and soft tissue tumours. Dr Boyle has particular experience and interest in hip and knee replacement, complex revision surgery, and bone and soft tissue tumour surgery, especially biological reconstruction and advanced joint replacement techniques including computer navigation and patient specific surgery, robotics and 3D printing.

Dr Boyle is a Fellow of the Australian Orthopaedic Association and previous Chair of The Northside Orthopaedic Training Scheme. He is a member of the International Society of Limb Salvage and the Australian and New Zealand Sarcoma Association.

Dr Boyle is involved in a number of clinical trials and prosthetic design teams for tumour treatment as well as in orthopaedic surgery and arthroplasty. He is the Medical Director of the NSW Bone Bank, and current Chair of the Sarcoma Clinical Group of the NSW Cancer Institute.

James Parr Osteosarcoma survivor, triathlete, model, disability advocate, writer, proud Wiradjuri boy

James Parr is a Melbourne based right below knee amputee, sharing his story and lived experiences to champion inclusion and representation for the disabled community within mainstream media/fashion industries. He was diagnosed with osteosarcoma in 2019 which resulted in an amputation of his lower right leg. James has used this experience to highlight the negative connotations and attachments surrounding disability as a force to create more representation in mainstream media to rewrite the narrative that having a disability is sad, to a new, more realistic narrative that people with a disability are seen as happy, valuable members of society.

As a Queer, First Nations Triathlete, James has represented not only at Melbourne Fashion Week & Melbourne Fashion Festival, but to Australian Afterpay Fashion Week. His passion for disability advocacy can be seen through his content creation and fast growing modelling career – which has seen him feature in the likes of Vogue and GQ Australia. Modelling for the likes of The Iconic and featuring in campaigns for Champion and a lululemon ambassador,

James likes to challenge the concepts of masculine and feminine through fashion. James’ creative career is complemented by his work Education Support and Student Welfare. Striving to set a positive example for the emerging generations of change makers, by aiding and working with them through disadvantages, trauma, learning difficulties, disabilities etc. James is also currently on the committee for Equity, Diversity, and Inclusion Advisory Group for the board of Triathlon Australia.

Dr Maurice Guzman Orthopaedic Surgeon; Member of the RPA Bone and Soft Tissue Sarcoma Unit

Dr Maurice Guzman is an Orthopaedic Surgeon who specialises in hip replacement and robotic knee replacement surgery, orthopaedic trauma, in addition to bone and soft tissue tumours in adults and children. Dr Guzman is one of only a few Orthopaedic Surgeons in NSW with expertise in the surgical management of patients with bone and soft tissue tumours. He is a Fellow of the Australasian College of Surgeons (FRACS) and the Australian Orthopaedic Association (FAOrthA).

Dr Guzman has completed specialist training in arthroscopic and reconstructive joint surgery and hip and knee replacement surgery in Australia. He later relocated to the UK to complete a fellowship at the highly prestigious Royal National Orthopaedic Hospital in London, specialising in bone and soft tissue tumours and complex joint replacement surgery. In addition to this, Dr Guzman completed observerships in Italy to refine his knowledge and skills in the surgical management of patients with bone and soft tissue tumours. He is actively involved in research and work has been published in several prestigious Orthopaedics journals.

A/Prof Wayne Nicholls Director, Oncology Services Group Queensland Children’s Hospital; Clinical Director, Ian Frazer Centre for Children’s Immunotherapy Research, University of Queensland

Associate Professor Wayne Nicholls is the Director of the Oncology Services Group (OSG) at the Queensland Children’s Hospital and the Clinical Director of the University of Queensland’s Ian FrazerCentre for Children’s Immunotherapy Research. His clinical and research interests are in paediatric, adolescent and young adult (AYA) solid tumours and other rare cancers. His interest in Paediatric, Adolescent and Young Adult (AYA) cancer is largely driven by the unchanging and unacceptable outcomes for young (and old) patients with sarcoma that have not changed for over 40 years.

His current research collaborations are directed towards developing novel therapies for high risksarcomas including as a coinvestigator (CI) on the recently awarded MRFF grant: Personalising Innate-immunotherapy for Superior Treatment Outcomes with Large anticancer applicability (PISTOL), on the ANZSA Grants: “Harnessing CRISPR-Cas13 to ablate “undruggable” sarcoma drivers”and “Targeting and eliminating Paediatric cancers with chimeric antigen receptor engineered natural killer cells, a new hope for cancer immunotherapy” as well as on the Tour de Cure Senior ResearcherGrant, “Investigating the quantity and quality of T cells in paediatric solid tumours”.

Neil Gibson
Father to Jack (dec) osteosarcoma;
Director of the Jack Gibson Sarcoma
Patient & Family Support Programme

Neil Gibson is the Father of the late Jack Gibson, sarcoma patient from 2017 to 2022. Neil is a retired company executive who these days spends his time on his Manning Valley farm or a golf course. Neil saw first hand how patients and families are dealt with (or not) during the gruelling surgery and treatment regime.

Neil, his wife Suzie and children Harry and Lily are determined to continue to drive a passion Jack had for better outcomes for Sarcoma families and patients, and are working hard to raise funds for the Jack Gibson Sarcoma Patient and Family Support Program, located on the CRBF website.

Rebecca Minty
Mother of Zac (forever 11) Rhabdomyosarcoma;
Founder Bricks & Smiles

Rebecca Minty is mother of Zac (forever 11), Elliott (9) and Sebastian (3), and lives in Canberra. Zac was 8 years old in 2019 when his left eyelid started to droop slightly. Further investigations led to the diagnosis of Rhabdomyosarcoma (RMS) in the orbit of his eye, and he underwent six months treatment including chemotherapy and radiation. After 9 months cancer free, the cancer returned. Zac had surgery to remove his right eye and orbit and from then on he was constant treatment, fitting in as much school and soccer as possible between weekly trips to Sydney for treatment. Sadly, Zac passed away on 29 May 2022.

Rebecca and her family have set up Bricks & Smiles: the Zac Minty legacy project to honour Zac's desire to help others going through what he went through. LEGO was so important to Zac through his treatment as a pastime, a rehab tool, a challenge, and an escape from treatment. Bricks & Smiles lets kids undergoing oncology treatment to pick out their dream LEGO sets, and fundraises for research into rare cancers.

Rebecca's professional background is in human rights law, and in her current role promotes oversight of places of detention.

Associate Professor Antoinette Anazodo OAM
Paediatric and Adolescent Oncologist
and Clinician Academic University of New
South Wales

Associate Professor Anazodo trained in Paediatric and Adolescent Oncology in the United Kingdom, completing a postgraduate diploma in Adolescent Oncology and fellowship training in Paediatric and Adolescent Oncology at the Kids Cancer Centre at Sydney Children's Hospital.

Associate Professor Anazodo has extensive clinical and managerial experience in the delivery of Youth Cancer Services for 15- to 25-year-old patients and is recognised in Australia as one of the leaders in the care of Adolescent and Young Adult (AYA) cancer patients with a comprehensive understanding of the issues specific to all AYA patients and the common cancers seen in this age group (sarcoma, lymphoma, leukemia and reproductive tumours). Associate Professor Anazodo has been committed to local, national and international improvements in the care of AYA patients that are in line with the NSW Youth Health Framework and the Strategic Health Plan for Young People and families and is recognised in Australia as one of the leaders in the care of AYA patients.

Associate Professor Anazodo has a strong research interest in AYA medical and psychological care during and after treatment and has built a practice is an expert in oncofertility and the reproductive care for cancer patients.

Associate Professor Anazodo has received a number of awards for her clinical and research work including a Champions Award from Prince of Wales Hospital, Pride of Australia award in 2015, Churchill Fellowship in 2015, nominated for Women of the Year in February 2016. In 2018 Dr Anazodo received the 'NSW Cancer Institute Premiers Rising Star Award', 'People's Choice winner for NSW Health Awards Integrating Health and Premiers Award for Improving Government Services. Finalist in UNSW 3M Thesis Awards. Nomination for Research Australia Health and Medical Research Award (Discovery Award) in 2020. In 2021 Associate Professor Anazodo was awarded an Order of Australia (General Division) for her contributions to AYA and Oncofertility Medicine.

Dr Daniel Franks
Orthopaedic Surgeon; Member of the RPA
Bone and Soft Tissue Sarcoma Unit

Dr Franks graduated with Honours from the University of Sydney Medical Program. He predominantly completed his orthopaedic training in Sydney but also gained invaluable experience through terms at other locations throughout NSW including Gosford, Newcastle, and Orange.

He has undertaken further sub-specialty training in robotic knee and hip arthroplasty, revision arthroplasty, bone and soft tissue tumour surgery, and complex reconstructive and limb salvage surgery. Prior to commencing medical training Dr Franks graduated with Honours in Biomedical Engineering at the University of Sydney and developed devices as a design engineer.

He continues to have a particular interest in integration of technologies such as custom device design, 3D printed implants, computer navigation, and robotic assisted surgery to deliver patient specific solutions to complex limb and joint reconstructions. Dr Franks has

been involved in various research projects and has publications in a number of surgical and orthopaedic journals. He has presented at national orthopaedic conferences and meetings, and is strongly committed to ongoing involvement in research, and his own professional development.

Kaela Graham-Bowman
Sarcoma patient and nurse

I am a mother, a veteran and a nurse. I was first diagnosed with synovial sarcoma in February of 2020. At that time I had just finished working in oncology and thought it was a sports injury, however after some scans- it was made very apparent it wasn't.

I then had emergency surgery to remove the tumour that was almost wrapping my femoral artery in my thigh. This was followed by IV chemotherapy (to which I suffered significant side effects) and radiotherapy. I was then cancer free for almost two years before relapsing and finding bilateral lung metastasis.

I first underwent a VATS to the right lung, however by the time I was scanned again, I was told they were back. I was started on more IV chemo which was unsuccessful and was told I'd now be inoperable and started on oral chemo called pazopanib.

I heavily advocated for myself for more surgery and was told if pazopanib held my tumours steady they would consider. 3 months of pazopanib, my tumours halved in size and I begged for surgery... my doctors listened. I then had a left VATS followed by a right side thoracotomy two weeks later. The latest scan shows no signs of cancer and I continue to take oral chemo whilst working as a nurse in the emergency department. My biggest passion is raising awareness about sarcoma, educating others and talking about self advocacy

Neema Rajak
Principal carer to brother Nikesh
living with osteosarcoma

From the tranquil hills of Nepal to the bustling corridors of the New South Wales Health Hospital, my journey has been a testament to my unwavering dedication to making a positive impact on people's lives. Born and raised in Nepal, my passion for effecting change blossomed during my formative years, ultimately leading me to the esteemed position of Nursing Unit Manager at NSW Health.

My path towards healthcare and service began to take shape during my high school days when I eagerly volunteered at a local orphanage in Nepal during school holidays. Those experiences illuminated the profound impact one could have on the lives of others through compassion and care. This revelation steered me toward a career in nursing, where I could transform my passion into a lifelong mission. Upon completing

my education, I embarked on a professional journey that has spanned years of dedication and hard work. Currently, I proudly serve as the Nursing Unit Manager at NSW Health. In this role, I oversee and coordinate a dedicated team of healthcare professionals, working tirelessly

to ensure the well-being and recovery of patients under our care. It is a role that constantly challenges me and keeps my commitment to healing and service alive.

Unfortunately, life has presented me with a profoundly challenging chapter. In December 2021, my younger brother received a heart-wrenching diagnosis of Osteosarcoma. This unwelcome entry into the world of rare diseases thrust me into a role that no one ever anticipates. Since that day, I have tirelessly immersed myself in researching treatment options, collaborating closely with my brother's dedicated medical team. This experience has not only deepened my knowledge of healthcare but has also strengthened my resolve to advocate for those affected by the same disease.

My story continues to evolve, but my unwavering commitment to healing and advocacy remains constant, driving me to push boundaries and make a difference wherever I can.

Louise Hird
Clinical Psychologist, Psychoanalyst,
Child and Adolescent Therapist/Supervisor/
Founder - CRBF psychological & emotional
support programme

Louise is a Clinical Psychologist, Psychoanalyst and Child and Adolescent Therapist, and Director, The Winn Clinic a not for profit psychotherapy Clinic. The Clinic arranges in depth consultations and referrals for treatment for treatment for adults, adolescents and children. She has training in the assessment and treatment of a broad range of mental health difficulties. Louise trained as a Psychoanalyst and has extensive experience in long term work with adolescents and individuals who are struggling with emotional and psychological issues.

Louise is an Honorary Lecturer at the Faculty of Medicine, Macquarie University, and is a member of the Australian Psychological Society Clinical College, the Australian Clinical Psychology Association, the Australian Psychological Society and the Australian Psychoanalytic Society. She is registered to practice with the Australian Health Practitioner Regulation Agency (AHPRA).

Louise has been immersed in supporting those living with sarcoma and their families for over three years, and founded the CRBF psychological and emotional support programme. Tragically, she has a great deal of personal experience with sarcoma which has led her to volunteer tirelessly in this capacity.

**Professor Peter Grimison
Medical Oncologist RPA
and Chris O’Brien Lifehouse**

Associate Professor Grimison is a Staff Specialist in Medical Oncology at the Chris O’Brien Lifehouse in Sydney, Visiting Medical Officer at RPA, and Clinical Associate Professor at the University of Sydney.

His clinical work focuses on testicular cancer, other genito-urinary cancers, and upper gastro-intestinal cancers. He serves as a member of the Australian Government Pharmaceutical Benefits Advisory Committee, and a number of other Federal and NSW Government committees. He is also committed to teaching as coordinator of Advanced Training in Medical Oncology at Chris O’Brien Lifehouse, and also actively teaches in Basic Physician Training and the University of Sydney Medical Program.

As a member of the Sarcoma Unit, Associate Professor Grimison reviews patients for consideration of chemotherapy and other systemic therapies, contributes to multi-disciplinary assessment and management decisions, contribute to research databases and recruits patients to clinical trials.

**A/Prof Angela Hong
Radiation Oncologist, RPA and
Chris O’Brien Lifehouse**

Associate Professor Hong is a radiation oncologist at Chris O’Brien Lifehouse with a strong track record in clinical and basic science research. She has a strong interest in melanoma and skin, bone and soft tissue tumour (sarcoma), lymphoma and stereotactic radiosurgery.

Associate Professor Hong graduated from the University of Sydney and completed her internship in Sydney before travelling abroad. She first gained experience in radiobiology research at the Memorial Sloan Kettering Cancer Centre, New York and at the University of California, Davis before returning to Australia to start her specialist training in radiation oncology. She acquired fundamental molecular biology and cell culture knowledge during her Master and PhD candidatures at the University of Sydney. She continues to apply this knowledge to advancing the field of clinical radiation oncology.

She has been a member of the Multidisciplinary Bone and Soft Tissue Tumour Clinic at Royal Prince Alfred Hospital for the past 15 years. As a clinician scientist, her research focuses on developing innovative radiation therapy technique and combination treatments to improve the outcome of patients with bone and soft tissue tumour. She is a principal investigator of clinical trials in sarcoma. Angela Hong is also an executive board member and co-chair of the scientific advisory meeting of the Australia and New Zealand Sarcoma Association.

**Professor David Thomas
Director, Centre for Molecular Oncology,
University of New South Wales;
Chief Executive Officer, Omico: Australia
Genomic Cancer Medicine Centre;
Laboratory Head, Genomic Cancer Medicine,
Garvan Institute of Medical Research**

Dr Thomas is a National Health and Medical Research Council L3 Investigator and inaugural Director of the University of New South Wales Centre for Molecular Oncology.

As a clinician-scientist, he applies genomic technologies to the understanding and management of cancer.

Dr Thomas founded the Australasian Sarcoma Study Group and Australia’s leading adolescent and young adult cancer unit at the Peter MacCallum Cancer Centre. Dr Thomas leads the International Sarcoma Kindred Study, now recruiting from 23 centres in 7 countries, and led the first international study of denosumab in Giant Cell Tumor of bone, leading to FDA approval and PBS reimbursement. He co-led a meta-analysis of the use of whole-body MRI in Li-Fraumeni Syndrome, which has changed management guidelines internationally.

In 2019, he established the Australian Genomic Cancer Medicine Centre (Omico), a national precision medicine program for patients with rare and early onset cancers.

This program has enabled more than 7,000 Australians with advanced cancers to access genomic profiling, and matched therapies through clinical trials, leading to improved survival.

**Emma Pechey
General Manager Sony Foundation Australia**

Emma Pechey is General Manager at Sony Foundation Australia, the charity arm of the Sony group of companies. Emma overseas the operations for the Foundation’s ‘You Can Stay’ accommodation program providing free accommodation for regional and rural youth cancer patients who must travel to the city for their treatment. Sarcoma patients are the highest referred cancer group to this program.

**Dr Owen Hutchings
Clinical Director, RPA Virtual Hospital**

Dr Hutchings is the Clinical Director of RPA Virtual Hospital (Sydney), a Hospital Generalist Staff Specialist and Fellow of the Australian College of General Practitioners (FRACGP). Owen has extensive experience consulting patients in hospital based Urgent Care and Acute General Practice environments including as a Hospital in The Home specialist providing hospital type care to patients in the community. Dr Hutchings has experience in acute hospital and critical care

specialties, holds Diplomas in Child Health, Obstetrics and Gynaecology and has proven success establishing innovative clinical models which integrate care between inpatient hospital and outpatient community settings including Primary Care.

**Mandy Basson
Mother of Abbie (dec) Ewing sarcoma;
Executive Director Sock it to Sarcoma!**

Mandy Basson is the Executive Director of Sock it to Sarcoma!, a health promotion charity based in Perth, Australia. Sock it to Sarcoma! was the vision of her daughter Abbie, who was diagnosed with Ewing’s Sarcoma! at the age of 17. Abbie was determined to create an organisation to raise awareness, fund research and give support to the sarcoma community with a firm belief that those diagnosed with a rare cancer such as sarcoma should have equal access to everything that was available to people diagnosed with the common cancers. Her ethos is the energy driving the Foundation. When Abbie passed away at the age of 20, Mandy continued to progress Sock it to Sarcoma! as Abbie would have wished, focused on improving outcomes for the sarcoma community by providing support for people diagnosed with sarcoma and their families at all stages of the sarcoma journey, raise community and health profession awareness for early detection and diagnosis, and invest in increasing research capacity through career support, translational research for effective treatments and psychosocial support for individuals impacted and their families.

**Karen Atkins
Mother/carer to Imogen, Osteosarcoma
survivor, Paediatric and Adult Palliative
Spiritual Care Practitioner**

Karen is the grateful Mum of Osteosarcoma survivor Imogen Atkins, who was diagnosed in January 2017, aged 15, with advanced osteosarcoma in her right femur and knee; tumors were also discovered in her lungs. Karen lives with the hope for Imogen’s continued wellness and watches in awe and wonder at her daughter’s inner strength, courage and beauty.

Karen’s lived experience in navigating the landscape as carer during Imogen’s treatment and recovery gave her an insight into the importance of companionship through the traumatic journey sarcoma takes you on. It also brought deep awareness for the lack of psycho-social and spiritual support for patients and carers. This greatly influenced a career shift into Paediatric and Adult Palliative Care Hospices in Queensland as a spiritual care practitioner.

**Dr Vivek Bhadri
Paediatric and Adolescent Medical
Oncologist, Chris O’Brien Lifehouse;
Adolescent Medical Oncologist,
Westmead Hospital and RPA; member of the
RPA Bone and Soft Tissue Sarcoma Unit**

Dr Bhadri is a paediatric and adolescent medical oncologist at Chris O’Brien Lifehouse and RPA. He trained in paediatric oncology in Sydney before completing an AYA fellowship at RPA. Dr Bhadri has extensive experience with the treatment and management of adolescent and young adult patients with bone and soft-tissue sarcomas, and actively participates in the development and implementation of sarcoma clinical trials.

Group findings

Sydney Local Health District would like to acknowledge and thank the patients, their families and carers that gave up their time to participate in a number of workshops, that helped us develop today's agenda. While there isn't time to cover everything discussed at the workshops, the below findings and today's discussions will help us to further improve and enhance our services.

Themes – What is working well?

- Multidisciplinary Team (MDT) collaboration and access to a variety of health professionals and organisations
- Initial diagnosis and treatment once with the specialist services (pace and access)
- First line treatment
- Confidence in specialist clinicians
- Respite support such as Bear Cottage, Ronald McDonald House, and adult hospices
- Nursing staff support

Themes – What are the challenges?

- Ability to access a range of expert opinions/2nd opinions without bias or judgement
- Impact of multiple diagnoses
- Reoccurrence of sarcoma
- Timeline for referral to clinical trials often after the first recurrence
- Referral to genomic screening at the earliest appropriate stage – i.e. if metastases are present at diagnosis, or recurrence of disease.
- Sourcing of relevant clinical trials
- Ongoing impact of sarcoma on survivors i.e. physical, financial, psychological impacts
- Financial and social impact to patients and families at diagnosis and throughout
- Limited mental health and psychosocial support
- Barriers to new treatment options in Australia which are available in other countries
- Treatments not approved under the Pharmaceutical Benefits Scheme (PBS) for sarcoma- families faced with being offered experimental treatments that they simply cannot afford
- Delays in diagnosis by GPs
- Education about sarcoma (not limited to) for frontline health professionals – dentists, accident and emergency doctors, physiotherapists, school nurses, trainers (professional sports teams) and GP's
- Regular complications with illness
- Transition – Child to adult care and transition of

decision making. Issue with 17 seen as an Adolescent and Young Adults (AYA's) treated as adults from a clinical perspective, but many do not have that level of maturity to face a sarcoma diagnosis and treatment.

- Accommodation including private rooms in public hospitals – currently young people sharing rooms with an array of cancer types and ages which impacts psychologically. Senior patients on palliative pathways or with dementia placed with AYA's.
- Teaching hospitals not being equipped to deal with sarcoma – a cancer that does require a high degree of specialty. Parents understood this to be the case, but felt it added another layer of angst to their child.
- Changes of doctor (rotations, retirement, annual leave etc)
- Family research time trying to find treatments, trials and answers
- Specialist care in major capital cities only – regional families are still disadvantaged
- Seen as an individual journey rather than a family journey – family members often
- overlooked for support
- Health literacy – it is often assumed all patients and families understand what is being communicated to them. Sarcoma is a particularly challenging cancer even to those immersed in it.
- CALD (Culturally and Linguistically Diverse) support. Because sarcoma affects all age groups and all parts of the body, it casts the net very wide, and Australia has such a strong multi-cultural focus. It is often the role of one family member to receive information and to communicate it to other family members
- Breakdowns in communication between treating teams, particularly across campuses.
- Pain management, especially at end-of-life care
- Connection with not for profits that provide an array of support services for the patient and family

Themes – What does the future look like?

- Private rooms and more options for family to stay, with comfortable beds. Because most sarcomas require very intense treatment regimes, the length of hospital stays can often be long, and difficult for the family unit
- Sarcoma care coordinator roles – to alleviate the burden on MDT's, the health system and most importantly, the patient and family
- Consumer/Family groups to share, learn and advocate together (such as this meeting)
- Improved, accessible and affordable mental health and psychosocial support
- Individualised support
- A more comprehensive offering of support groups for patients and families (including peer support)
- Young widows groups – this is an emerging need as there has been an upward trend observed by support organisations in the diagnoses of young men/women in the 25-40 age group. These young people often have young families or a partner.
- Support for paediatric patients and their families transitioning from the paediatric system to an adult campus. This is a tumultuous time for both patient and family, and requires sensitive handling and management
- Immediate improvement of support for people who live rural, remote or distance from major treatment centres.
- Nurse led models e.g., nurse practitioner roles which can perform scan referrals, pathology requests and prescribing of schedule 2, 3 and 4 drugs in the absence of doctors
- National website on sarcoma online resources that is being developed by the Curtin University, Cooper Rice-Brading Foundation, and Sock It To Sarcoma!
- Access to patient advocates in hospital
- Genomic screening offered from diagnosis
- Clinicians supporting second opinions

Notes

