

## Scottish Sarcoma Network (SSN)

Volume 1 Issue 1 – July 2020

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### Headline

Welcome to the first issue of our newsletter.

The newsletter will be published biannually and if you have any news that you feel would be of interest to the network members please let us know and we will include it in subsequent editions.



I would like send a message to all the members of the Scottish Sarcoma Network (SSN) for their hard work, engagement and resilience through this challenging time. The pandemic has changed the ways we work. We are all called to rapidly adapt to the changes around us and take action to ensure best care for sarcoma patients across Scotland.

I have **three** messages for you today.

- ✓ A **message of acknowledgement** – we have to acknowledge that current times are difficult for everyone; patients, carers and clinical teams.
- ✓ A **message of acceptance** – we have to accept current times are difficult to us all.
- ✓ A **message of gratitude** – I am thankful to you all for your hard work and efforts.

Look after yourselves and look out for each other. This first SSN Newsletter during COVID-19 will ‘remind’ us all of our successes over the last year, celebrate the harvest and plant the seeds for the future.

*Dr Joanna Nixon, PhD, MPH, FFMLM  
 Consultant Clinical Oncologist  
 and Scottish Sarcoma Network’s Clinical Lead*

## Scottish Sarcoma Network and BSG host the British Sarcoma Group 2020 Conference in Glasgow

It was only four months ago we were all together at the BSG 2020 Conference, which was extremely well received. Conference theme was on the concept of “What Matters to me” and togetherness, which was reflected on the programme. We should all be proud to have delivered a multidisciplinary, comprehensive and patient-centred conference.

*“An excellent meeting all round. Well done!”*

Dr Chris Nicholas

*“Brilliant event. Best BSG conference I’ve attended. Many thanks”.*

Miss Louise McCullough

*“Thank you so much again for your kind invitation and your outstanding hospitality. In the last two days, I had enjoyed your excellent BSG Conference and I had the opportunity to get familiar with the sarcoma community in the UK. It has been very rewarding, a very positive and informative experience. BSG Conference has been truly multidisciplinary, comprehensive and patient-centred event”.*

Antonio Cassado,

*“I really enjoyed it. The program had a high level of interesting frontier developments and science. Very inspiring!”*

Paul Yutte

*“Many thanks. I think this was one of the most interesting and collaborative BSG conferences I have attended. I do hope future BSG conferences will incorporate further science focused sessions. If I can help in any way do let me know”.*

Prof Sue Burchill, Professor of Adolescent and Paediatric Science

*“It is not often a member of the public gets to meet a group of specialists en masse. Every person who came to stitch the tapestry was a delight. Can I just say on behalf of those of us, who have been cancer patients; we are really privileged to be treated by people who care and have such expertise. So thank you!”*

Heather Swinson, Cancer Survivor and lead for first panel of Cancer Tapestry Project.

## SSN Shortlisted for the BMJ Awards 2020 under Cancer Care Team of the Year Category



<https://thebmjawards.bmj.com/shortlist/>

The National Sarcoma MDT improvement project was nominated for the awards and team was invited to participate as finalists under Cancer Team of the Year category.

The interviews and ceremony were scheduled for the 22nd April 2020; however had to be deferred until October 2020 due to the pandemic. New dates are to be confirmed. Other candidates are Swansea Bay University Health Board (Rapid Diagnosis Centre), University Hospitals of Leicester NHS Trust (Lung Ca Emergency Presentation), Oxford University Hospitals, NHS Foundation Trust and Oxfordshire CCG (SCAN pathway), Royal London Hospital, Barts Health NHS Trust (Children with Retrinoblastoma).

The “National Sarcoma MDT project”, initiated by Dr Ioanna Nixon and co-led by Dr Mark McCleery and Lindsay Campbell on behalf of the Scottish Sarcoma Network, is a national forum for discussions and decision making on the optimal treatment and care for all patients diagnosed with sarcoma.

Sarcomas are rare and diverse cancers that can develop in any part of the body and are 1% of cancers in Scotland. On average 350 patients are diagnosed each year in Scotland but this number is rising, and the MDT ensure the complex care required for patients is co-ordinated between the multiple sites.

Early diagnosis and pathology input is essential for every patient with sarcoma and the Scottish sarcoma multi-disciplinary team (MDT) aims to ensure equitable, timely, safe and person centred care for all patients.

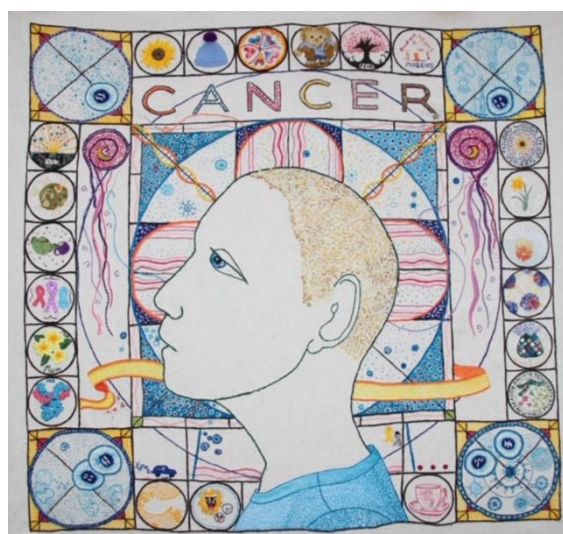
Dr Nixon said: “We are delighted we are finalists for the BMJ awards. This is a boost for everyone who has worked extremely hard to support reform work for all cancer patients in Scotland. This includes the team, clinicians, pharmacists and GP colleagues.”

“We also work with patients to improve the patient experience. This feedback from patients on how we make improvements is a team effort. Using science helps us to plan, coordinate and deliver an improvement project. But the recipe for success lies in the common purpose and shared vision.”

“We are all together on a journey to improve care for our patients and their families.”

“If, as Hippocrates says, we have a love of medicine, we, the National Sarcoma MDT, shall share this love in all dimensions of our professional life.”

## The Cancer Tapestry



### The beginning:

The Cancer Tapestry is designed by Andrew Crummy, who designed The Great Tapestry of Scotland and other tapestries. The idea of the Cancer Tapestry was launched in Falkirk at the RISE (Resilience: Inform, Support, Empower) sarcoma event organised by Dr Nixon, Andrew’s oncologist, for patients and carers in 2018. During that event, Andrew shared his own journey and spoke about how his art, his family and the medical team helped him cope during his cancer treatment. He also shared the idea of a tapestry on cancer and this was massively endorsed by the patients and their carers.

Rod Mountain, ENT Surgeon and educator in Ninewells inspired Andrew to use his art to do a tapestry about cancer.

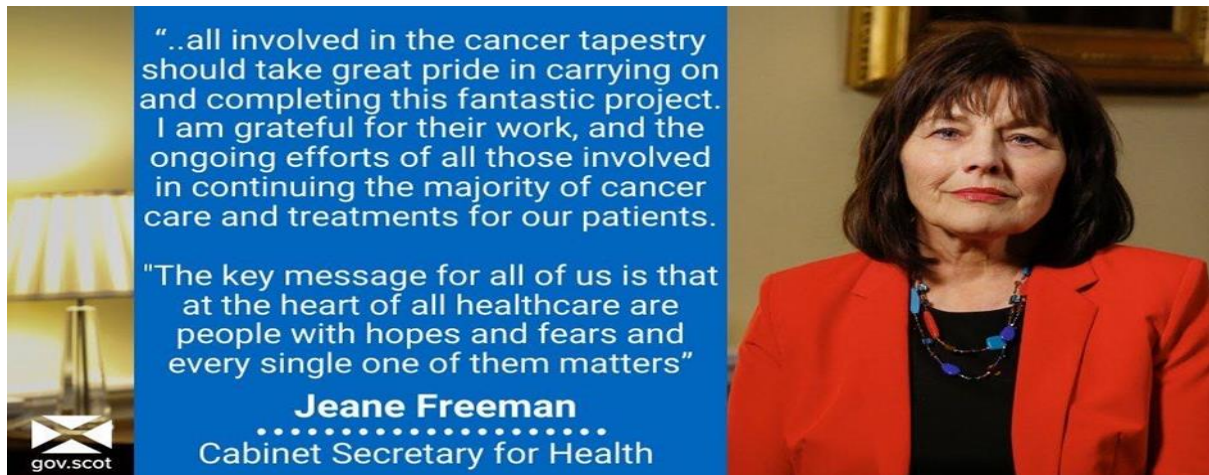
The Cancer Tapestry was launched at the Scottish

Parliament on the 4th February where Andrew Crummy, Rod Mountain and Dr Nixon met with Jeanne Freeman, Cabinet Secretary of Health. The first stitch was added by Jeanne Freeman at the heart of the tumour.

### Final Stitch of the first panel:

On the 26th May 2020, the final stitch of the first panel was added by Heather Swinson, a cancer survivor and lead for the first panel. The final stitch was due to be added by Health Secretary Jeanne Freeman MPS, however lockdown meant stitcher Heather Swinson had to do it herself during an online closed ceremony attended by Ms Freeman, Andrew Crummy, Dr Nixon and Mr Mountain.

*Ms Freeman said at the ceremony:*



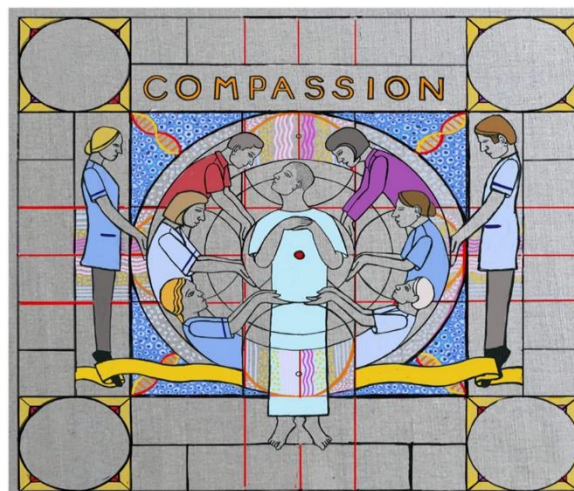
The original aim of the Cancer Tapestry was to tell 1000 stories of Cancer, to show the compassion and caring that happens from NHS staff, family and friends. The original sketches by Andrew, completed during his treatment, show his journey through an 8 month treatment.

Each panel is surrounded by 10cm Cancer Cells, stitched into each cell is an individual story. The Cancer Cells kits are organised by Gillian Hart and have been sent out as far as Mexico, USA and South Africa.

The Cancer Tapestry has currently 8 panels being stitched and more panels planned in East Lothian, Glasgow, Dundee, Walton on Thames and Leeds. For more information contact Gillian Hart at [cancertapestry@gmail.com](mailto:cancertapestry@gmail.com).

- ✓ A short film by Jo Allen, Heather’s daughter telling Heather’s journey stitching the panel: <https://youtu.be/-fdZqdlC13c>
- ✓ Cancer Tapestry first panel, first stitch: <https://www.facebook.com/groups/679610722614027/>
- ✓ Cancer Tapestry: <https://www.facebook.com/groups/246710202924436/>

**The next panel is Glasgow panel on compassion. Will you help us by adding a stitch?**





## Novel Research

ICR and Royal Marsden researchers have been awarded a £2.5m grant to set up the world's largest digital hub of sarcoma research data. This 5 year project is led by Dr Robin Jones, at The Royal Marsden NHS Foundation Trust.

SSN is having one of the leading roles in the Consortium. Dr Nixon, Dr White and CTU in Glasgow are leading on one the study workstreams on behalf of the consortium and Dr Hayward in Edinburgh is also part of the collaborative. Co-Investigators on the project include teams based at University of Birmingham, Instituto Nazionale dei Tumori-Milano, and Instituto de Biomedicina de Sevilla.

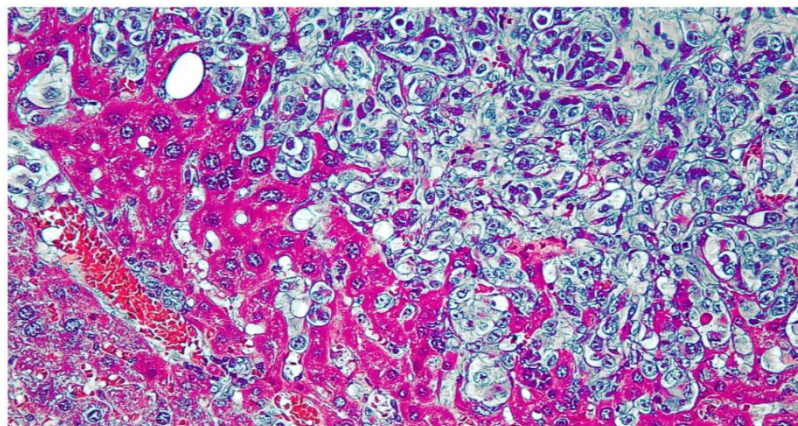


Image: Metastasis in a Kaposi sarcoma mouse model. Credit: [Anthony B. Eason](#) via NIH Image Gallery on flickr, [CC BY-NC 2.0](#)

The CRUK announcement is:

<https://www.icr.ac.uk/news-archive/world-s-largest-sarcoma-research-database-aims-to-revolutionise-sarcoma-treatment-after-multi-million-pound-investment>

This collaboration is in line with the [Scottish Sarcoma Research Strategy](#).

## SSN Collaboratives

**Breast Cancer collaborative**, led by Mr Steven Lo: Collaboration with the West of Scotland Breast Cancer Managed Clinical Network to produce consensus guidelines for the management of breast sarcomas with Dr Janet Litherland, Dr Mark McCleery, Dr Elaine MacDuff, Mr James Mansell, Dr Sophie Barrett, Dr Fiona Cowie, Dr Jeff White and Dr Ioanna Nixon.

**Head and Neck Sarcoma collaborative**, led by Dr Ioanna Nixon: UK wide collaborative to produce consensus guidelines for the management of head and neck sarcomas. A UK wide survey was led by Dr Nixon to understand current pathways in the management of head and neck sarcomas in the UK. The survey was developed with the support of Professor Jim McCaul (WoS Head and Neck Cancer MCN Lead), Dr Fiona Cowie, Mr Jeremy McMahon, Mr Steven Lo, Dr Aisha Miah, Mr Nicholas Kalavrezos (The London Sarcoma Network), Professor Vin Paleri (The Royal Marsden, BAHNO), Dr David Thomson (Christie), Mr Stuart Winter (Oxford), Dr Bernie Foran (Sheffield), Professor Peter Brennan (Portsmouth). The survey was endorsed by the British Sarcoma Group (BSG) and British Association of Head & Neck Oncologists (BAHNO). Through the survey it was evident there is need to develop UK consensus guidelines. Dr Nixon in collaboration with BSG is taking this forward.

**Skin Cancer collaborative**, led by Mr Steven Lo: Collaboration with the West of Scotland Skin Cancer Managed Clinical Network to review consensus guidelines for the management of skin sarcomas with Dr Ruth Blair re-auditing practice for 2015-2019.

**Follow-up collaborative**, led by Dr Ioanna Nixon: Survey of patients/carers and Clinicians across Scotland on the use of telemedicine before reviewing the follow-up guidelines for sarcoma.

**SSN COVID-19 rapid response group**, led by Dr Nixon: The group aims to ensure fluid communication, support and prompt action between all 5 sarcoma centres and has representation from all specialties; Mr David Boddie, Dr Trevor McGoldrick, Dr Annie Kennedy, Dr Michelle Fergusson, Dr Aisling Hennessey, Mr Sam Patton, Dr Mark McCleery, Dr Elaine MacDuff, Mr Ashish Mahendra, Mr Sanjay Gupta, Mr Pete Chong, Ms Martha Quinn, Mr Steven Lo, Dr Walter Mmeka, Marnie Black and Lindsay Campbell. The pandemic has generated joint guidelines from the British Sarcoma Group, British Orthopaedic Oncology Society and the UK sarcoma specialist centres.

## Education

The COVID-19 pandemic means our quarterly education days cannot go ahead in person and we are partnering with NHS Education Scotland on our first virtual education day.

### **Tailoring education on rare diseases to the trainee needs**

The induction of new trainees joining the sarcoma oncology team can be difficult, particularly given the diversity and rarity of sarcomas. As a first step to help and support our trainees an “induction sarcoma package”, was developed by Dr Nixon and Dr Colin Barrie, with the support of Dr Cowie and Dr White. The education material was endorsed by the local trainee committee. SSN is further evaluating this work through a trainee survey led by Dr Archana Ghave with the support of Dr Nixon.

## Audit

The Scottish Sarcoma Network has published year five (2018/19) of the sarcoma quality performance indicators and the report is available on the website at:

<https://www.ssn.scot.nhs.uk/audit>

The indicators will be reviewed after our sixth year is published (February 2021) and is scheduled to begin in December 2020.

## Website

A survey of the website by members of the Scottish Sarcoma Network was led by Dr Jeff White and Alan Abraham.

The survey confirmed the website is to provide the network-specific content and link to our Partners websites for the content they provided (e.g. Charities patient and carer information).

## Hello and cheerio

Catriona Graham left us for pastures new in August 2019 and then joined us for BSG 2020 in Glasgow. Alan Abraham took over from Catriona in December 2019 and is coming up to speed very quickly.

Gordon McInally started as TYA CNS and Nicola Heymans took over as Sarcoma CNS in Dundee in June 2020.

## Scottish Sarcoma Network Virtual Steering Group

Name	Specialty	Unit	Region
Ioanna Nixon	Consultant Clinical Oncologist and Scottish Sarcoma Network Lead	Glasgow	WoSCAN
Aisling Hennessy	Consultant Clinical Oncologist and Edinburgh Centre Lead	Edinburgh	SCAN
Alison Mitchell	Consultant in Palliative Medicine	Glasgow	WoSCAN
Ashish Mahendra	Consultant Surgeon and Surgical Lead	Glasgow	WoSCAN
Chris Nicholas	Consultant Radiologist and Joint Radiology Lead	Glasgow	WoSCAN
Debi Kirk	Lay Representative and Website Designer		
David Boddie	Consultant Surgeon and Aberdeen Centre Lead	Aberdeen	NCA
Donald Salter	Professor of Osteoarticular Pathology and Pathology Lead	Edinburgh	SCAN
Fiona Cowie	Consultant Clinical Oncologist and Oncology Lead	Beatson West of Scotland Cancer Centre	WSCAN
Jane Law	Clinical Nurse Specialist and Nurse/AHP Lead	Glasgow	WoSCAN
Jeff White	Consultant Medical Oncologist	Beatson West of Scotland Cancer Centre	WoSCAN
Larry Hayward	Consultant Medical Oncologist	Edinburgh	SCAN
Lindsay Campbell	National Managed Clinical Network and Improvement Manager	Glasgow	National
Lorraine Cowie	Regional Manager (Cancer)	NHS Grampian	NCA
Lorraine Stirling	Network Administrator and Webmaster	Glasgow	National
Mark McCleery	Consultant Radiologist and Joint Radiology Lead	Glasgow	WoSCAN
Michelle Ferguson	Consultant Medical Oncologist and Dundee Centre Lead	Dundee	NCA
Milind Ronghe	Consultant Paediatric Oncologist	Glasgow	WoSCAN
Peter Chong	Consultant Surgeon and Joint Glasgow Centre Lead	Glasgow	WoSCAN
Sam Patton	Consultant Surgeon	Edinburgh	SCAN
Steven Lo	Consultant Surgeon and Joint Glasgow Centre Lead	Glasgow	WoSCAN
Sinclair Dundas	Consultant Pathologist and Research Lead	Aberdeen	NCA
Stuart Hamilton	Consultant Surgeon	Edinburgh	SCAN
Walter Mmeka	Consultant Medical Oncologist and Inverness Centre Lead	Inverness	NCA

*Updated July 2020*