



**Annual Report for 2007 - 2008 plus 1<sup>st</sup> half of 2008 – 2009**

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## Lead Clinician's Report

The Scottish Sarcoma Network is now in its fourth year. There have been several key changes in the leadership and membership of the network since the AGM in November 2007. Tom Scotland is to be thanked for his even handed solidity in establishing the network and bringing us to where we are today. Paul Welford made a massive contribution, despite his management role being only temporary and supernumerary; he will be sorely missed. I welcome Lindsay Campbell as our new network manager and Ashish Mahendra to the surgical service in Glasgow. Both have already demonstrated valuable contributions to the effective running of the network, and I very much look forward to working with them in the future. With changes at both clinical and management level as well as illness amongst key staff, the transition has been challenging, and I greatly appreciate the support of the other members of the Project team.

The Network looks after the needs of a population of over five million people spread over a wide geographic area. The population density is far more akin to that of perhaps Norway or Ontario than that of our southern neighbours. It is our responsibility therefore to ensure that we provide a quality service for our patients close to home.

In forming the Network four years ago we started to bring together small teams working in relative isolation. Whilst we have good evidence that survival rates for osteosarcoma in Scotland have improved throughout the 20<sup>th</sup> century at least as well as the rest of the UK (1), our challenge in the new millennium has been and will continue to be based around the following criteria:

Ensuring our patients receive treatment by a co-ordinated specialist team in a timely fashion.

Care is joined up so patients can benefit from the full range of treatments, support, rehabilitation and services required for the successful management of their disease.

The effectiveness of treatment must be documented and a robust system for data collection and evaluation is required.

Education of clinicians, paramedical staff, and an awareness in the general population with regard to the diagnosis of sarcoma, as well as ensuring our patients continue to receive the highest quality up to date care available through the continual upgrading of skills within the specialist team.

Maintaining a research program, as the best clinical teams need to be both proactive and reactive to achieve improvements in care.

Efficient and well targeted use of IT.

In response to the above, the Network has made good progress to address issues in all areas including:

All patients with sarcoma are now discussed at a multidisciplinary team meeting (MDT). There are currently two weekly MDTs, one in Edinburgh (serving the SCAN network) and one in Glasgow (serving WOSCAN and NOSCAN). We have agreement from the clinicians to establish a pan Scotland meeting following the appointment of a coordinator whose funding has been approved and recruitment is anxiously awaited.

New appointments to the Network should show evidence of appropriate specialist training in the field of sarcoma.

We have put in place a number of quality assurance criteria to maximise care. For example, 2 consultant surgery for all endoprosthetic work and pelvic surgery. We have had our Quality Assurance Framework approved.

Care guidelines have been developed to encourage standardised management across the Network.

We have produced and disseminated information for general practitioners on referral guidelines for both osteosarcoma and soft tissue sarcoma. We have information for clinicians and patients available on our website.

We have an approved dataset with IT support for commencing a pan-Scotland clinical database. Its launch, however, awaits the appointment of an MDT coordinator to provide the administrative support for this necessary service. Until this occurs, it is recognised that data collection remains a serious weakness.

A specialist nursing module has been developed. Research remains active under the auspices of our research chair Daniel Porter, with publications from all areas of the Network. The British Sarcoma Group meeting is due to be hosted by the Network in Glasgow next year.

So where do we go from here? An option appraisal is awaited and may again change the way sarcoma care is delivered in Scotland.

It is important that we try to maintain a common view and a clear goal. I have been and continue to be impressed by the high standard of clinical care given in the Network. I am delighted that the individuals involved are committed to providing a top rate service, but most of all we are bound by a team spirit that is both rare and precious.

We have an opportunity to develop a world class service. My own view is that the Network (I dislike the term) should be regarded as a Scottish Sarcoma Service, separate of established geographical constraints based at one site, two sites etc, able to see patients at clinics close to home, perform surgery in places appropriate to do so (children's sarcoma in specialist children's hospital, brachial plexus sarcoma in a brachial plexus unit, para-spinal sarcoma with spinal surgeons and neurosurgeons). Care can be determined within the National MDT forum and commissioned by the Network at sites most appropriate for the patient's often unique requirements.

We are moving to a single MDT, we must collect and audit our data. Failure in this regard is not an option. We have established processes for ensuring continuing education and have IT plans to streamline referrals into the service.

I have no doubt that the coming option appraisal is a great opportunity for us to achieve our goals. However we must continue to focus on our service and results.

1. Foster L, Dall GF, Reid R, Wallace WH, Porter DE. Twentieth-century survival from osteosarcoma in childhood. Trends from 1933 to 2004. *J Bone Joint Surg Br.* 2007 Sep;89(9):1234-8.

## **Introduction**

### ***Description of the Network***

The Scottish Sarcoma Managed Clinical Network is now in its fourth year. The inaugural meeting was held in November 2004. The remit of the network is to register clinical, radiological, oncological and pathological details of patients with bone or soft tissue sarcomas throughout Scotland. It must provide a Scotland wide forum for service improvement and education. It must provide data for audit and research purposes.

Surgery for adult sarcomas takes place in 3 sites; Aberdeen, Edinburgh and Glasgow.

Surgery for paediatric and adolescent sarcomas takes place in 2 sites; Edinburgh and Glasgow

Oncological treatment is provided in 5 sites; Aberdeen, Dundee, Edinburgh, Glasgow and Inverness.

There are currently two multi-disciplinary team (MDT) meetings. A weekly Monday teleconferencing meeting links Glasgow, Aberdeen, Dundee and Inverness. Edinburgh holds its own weekly meeting on a Wednesday afternoon. A representative for the Edinburgh group sits in on the weekly teleconference link.

A single, weekly, national MDT is planned but has been contingent on the hiring of a Coordinator. This has not been achieved so far and is currently with NSD and the Network Manager for resolution. This will allow all new sarcoma cases to be registered and discussed nationally with local discussions taking place to supplement this.

A steering group meets quarterly. Its overall goal is the improvement of management of sarcoma patients in Scotland. The steering group reports back to the Annual General Meeting which is held in November.

### ***Purpose of the Network***

The purpose of the network is to optimise the treatment of patients with sarcoma in Scotland. Working groups were established to address key priorities:

1. Database and audit
2. Referral guidelines
3. Nursing and allied health professional group
4. Imaging protocols
5. Pathology protocols
6. Oncology and radiotherapy protocols
7. Research and education
8. Patient information and involvement

The strong links with the British and Scandinavian Sarcoma Groups have been maintained.

### **Services covered**

A wide range of clinical services are involved and locally funded, apart from the nationally funded Endoprosthesis service. NSD are currently conducting an Options Appraisal on this nationally funded service.

### **Network Resources**

0.33 WTE MCN National Manager.  
1-2 PA's for the Clinical Lead.  
Administrative support from WoSCAN.

### **Membership**

All health professionals with an interest in sarcomas are cordially invited to attend the Annual General Meeting.

The steering group (previously known as the project team) has the following members:

Mr Sam Patton	Lead Clinician/Orthopaedic Surgeon, Edinburgh
Dr Fiona Cowie	WoSCAN Lead /Oncologist, Glasgow
Dr Michelle Ferguson	NoSCAN Lead/Oncologist, Dundee
Dr Larry Hayward	SCAN Lead/Oncologist, Edinburgh
Dr Milind Ronghe	Paediatric Oncologist, Glasgow
Mr Daniel Porter	Orthopaedic Surgeon, Edinburgh
Dr David Ritchie	Radiologist, Glasgow
Ms Dawn Currie	Sarcoma Nurse Specialist, Glasgow
Ms Gill Harley (retiring and replacement being identified)	Teenagers and Young Adults Nurse Specialist, Edinburgh
Katie Hannah	Sarcoma Patient Representative, Aberdeen
Dr David Linden	General Practitioner, Ayrshire and Arran
Professor Paddy O'Dwyer	Abdominal Surgeon, Glasgow
Mr Stuart Hamilton	Plastic Surgeon, Edinburgh
Dr Alison Mitchell	Palliative Care Specialist, Glasgow
Professor Donald Salter	Osteoarticular Pathology, Edinburgh
Mr David Boddie	Orthopaedic Surgeon, Aberdeen
Mr Mike Jane	Orthopaedic Oncologist, Glasgow
Mrs Susan Groom	General Manager, Glasgow
Mr Lindsay Campbell	MCN National Manager, Glasgow

### **Clinical Facilities**

There are full facilities for primary oncological care at five centres.

There are full facilities for surgical sarcoma care at three sites.

There are full facilities for conventional diagnostic imaging at all sites.

Routine PET provision is available on request for sarcoma patients when necessary.

Prosthetic and orthotic support is available to basic NHS standards. There are areas of unmet need, eg provision of high quality and sports prosthetics.

Palliative care provision throughout Scotland is available at all sites.

### ***Clinical Quality Indicators***

1. GP's refer suspected sarcoma to a sarcoma centre as early as possible
2. All patients with a suspected sarcoma are seen at a Specialist Clinic
3. Imaging is undertaken by a Radiologist specialising in sarcoma work
4. Biopsy is taken either by a Surgeon or Radiologist with specialist interest in a sarcoma centre
5. All imaging and biopsy findings are discussed at the MDT to establish an accurate diagnosis
6. A definitive plan of clinical management is agreed by the MDT with patients entered into appropriate trials
7. There is multi disciplinary surgical input (e.g. orthopaedics, vascular, plastics, general, thoracic) to allow an appropriate surgical treatment plan to be developed
8. Resection specimen, pathology is fully and dually reported to the MDT to allow the MDT to determine response of bone tumours to chemotherapy and adequacy of margins, and to establish whether radiotherapy may be required post-operatively
9. Specialist nursing advice is provided by the sarcoma Nurse Specialist or Link Nurse with an interest in sarcoma
10. Each patient has a coordinated support package that includes;
  - a. Follow-up imaging
  - b. Follow-up oncology
  - c. Follow-up surgery
  - d. Palliative medicine
  - e. Access to prosthetics
  - f. Physiotherapy
  - g. Occupational therapy
  - h. Nutrition/dietary advice
  - i. Self help group
  - j. Psychological support

## **Activity**

### ***Specific service improvement accomplished***

1. A soft tissue sarcoma poster has been distributed to all General Practitioners throughout Scotland, with the aim of minimising delays in referring patients (NoSCAN audit indicates average time is reducing). It is also linked on our website ([www.ssn.scot.nhs.uk](http://www.ssn.scot.nhs.uk)) along with the link to the Cancer in Scotland website.
2. A core data set has been completed within ECASE and is ready to be launched but Clinicians have agreed that's it launch is contingent on the appointment of the National MDT Coordinator.
3. Surgical referral guidelines for hospital practitioners have been approved and published on the website, with the aim of minimising delay and maximising outcomes for patients (NoSCAN audit indicates the average times is reducing and outcomes are improving).
4. Palliative care guidelines have been approved and published on the website.
5. Scottish Bone Tumour Registry Meetings. Two of these meetings are now held in Glasgow (to review the registry), the other two meetings a year are held in Edinburgh and provide a forum for presenting research, audit and discussion of instructive or difficult cases.
6. Patient information leaflets are being developed in such a way as to be applicable nationally but funding has to be secured.
7. Imaging protocols are ready to be placed on the website.
8. Radiotherapy protocols are published on the website, with the aim of ensuring a minimum standard of care for the uniform delivery of radiotherapy for sarcoma patients across Scotland.
9. Chemotherapy protocols are in development and will then be published and updated on the website.
10. Our NHS QIS quality assurance framework has been approved.
11. The website links to GP referral guidelines for Cancer.
12. Orthopaedic referral guidelines are in development.
13. Head and Neck sarcoma guidelines are in development.
14. Thoracic metastases and primary thoracic sarcoma guidelines are in development.
15. Osteosarcoma poster has been disseminated to GPs.

### ***Meetings, Education and Courses***

The Annual General Meeting (AGM) was held on 2<sup>nd</sup> November 2007 at Perth Royal Infirmary and was attended by approximately 50 people.

The next AGM is planned for 28<sup>th</sup> November 2008 at Perth Royal Infirmary.

All AGM's are recognised for CME points.

The steering group met quarterly on 15th June 2007, 14th September 2007, 14th December 2007, 11th April 2008, 6th June 2008 and 12<sup>th</sup> September 2008. Minutes of these meeting are available from the MCN National Manager.

The next steering group is planned for 28<sup>th</sup> November 2008 (prior to the AGM) at Perth Royal Infirmary.

An education module for sarcoma at the University of West of Scotland is in preparation and due to start early 2009.

The British Sarcoma Group annual meeting will take place in Glasgow in March 2009.

### ***Audit Activity***

This is presented at the quarterly SBTR meetings and AGM.

17<sup>th</sup> September 2008 meeting received an interim report from NoSCAN. This report is available from David Boddie.

Pan Network audit data remains deficient but a clear pathway for rectifying this is established dependent on the appointment of a coordinator.

### ***Research and Teaching Activity***

A full report of activity in the Network over the year will be given by Daniel Porter at the AGM. Further data, including published papers, is available from Daniel at [Daniel.Porter@ed.ac.uk](mailto:Daniel.Porter@ed.ac.uk).

### ***Quality Assurance Framework (QAF)***

The network finalised and implemented our QAF in October 2007.

### **2008-2009 Work Plan**

1. Recruitment of National MDT Coordinator (unable to progress weekly pan-Scotland MDT Meeting and national data collection until in post)
2. Weekly national MDT meeting implemented
3. ECASE data collection to start
4. QAF finalised and implemented with QIS
  - a. Surgery
  - b. Radiology
  - c. Pathology
5. Protocols accessible by the public
6. Referrals streamlined and made electronic where possible
7. GP education in soft tissue sarcoma as each GP is likely to care for 1 patient with soft tissue sarcoma in their career
8. Ensure all patients in the network have access to a nurse skilled in sarcoma care

### **Finance**

The network is operating within budget.