

Scottish

Sarcoma



Network

## **Annual Report for 2006- 2007**

1. Lead Clinician's Report 2006-2007
2. Introduction
  - Description of the network
  - Purpose of the network
  - Services covered
  - Membership
  - Resources/facilities
  - Clinical Quality Indicators
3. Activity Report
  - Specific service improvements
    - accomplished
    - in progress
    - Planned
  - Number of meetings held and brief summary of meetings
  - Audit activity
  - Research/teaching activity
4. Plans for the year ahead
5. Finance

## **Lead Clinician's Report 2006/2007**

The Scottish Sarcoma Managed Clinical Network is now well into its third year and by the time the Annual General Meeting comes around in November 2007 I shall have completed my three years as Lead Clinician and will hand over the reigns of responsibility to another.

I am very grateful indeed to the members of the Project Team who have worked very hard to fulfil their responsibilities and given freely of their time and energies. I am also very grateful to those who have lead the various working groups who are usually but not necessarily part of the project team. The annual report illustrates the work that has been achieved over the past 12 months and the plans for the year ahead give an indication of the ongoing enthusiasm and vigour which prevails.

I am particularly grateful to Mr Paul Welford, NOSCAN Manager, who due to unforeseen circumstances, has had to provide a great deal of management support to the Network.

I would also like to acknowledge the help of our patient representative who has continued to play a very active role in the management of the network and has been supportive of other patients who have come into contact with the network. He and I visited the British Sarcoma Group Meeting in Manchester in February 2007 and he has now established strong links with patient representatives of the British Group.

The Annual General Meeting in November 2007 will have patient input as indeed our two previous Annual General Meetings have had. Our AGM's are now recognised for continuing medical education points and this should help ensure a good healthy turnout.

I hope that in the near future we shall be the first Scottish Cancer Managed Clinical Network to receive accreditation from NHS QIS. We submitted a quality assurance framework in March 2006 and after a year or so they got back to us with some amendments. We are pressing for a further meeting to complete our accreditation.

Data collection remains an ongoing problem. The data and audit group have done much hard work to produce a data set. We now need funding to employ an individual to enter the data.

We are hopeful that this funding may become available thanks to the re-definition of the Scottish Sarcoma Service. Up until now National Services Division has funded the endoprosthetic component of the Sarcoma Service. Following discussions with National Service Division in the past year, the nationally funded service will be re-designated to include the surgical treatment of all musculo-skeletal sarcomas. It is hoped that we may be able to obtain funding for a MDT Co-ordinator who would be ideally placed to enter all data.

Thus far the network has functioned well on good will and a desire by all concerned to provide a comprehensive high quality service for patients in Scotland. However, good will can only achieve so much and we do need funding to take the matter of data collection onward.

Tom Scotland  
Lead Clinician  
(May 2007)

## **Annual Report Scottish Sarcoma Managed Clinical Network**

### **Introduction**

Description of Network - The Scottish Sarcoma Managed Clinical Network is now in its third 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 sarcomas takes place in three sites, namely Aberdeen, Edinburgh and Glasgow. Oncological treatment is provided in these centres and in addition an oncological service is provided in Inverness and Dundee.

There are two mutli disciplinary team meetings. A weekly Monday teleconferencing meeting links Glasgow, Aberdeen, Dundee and Inverness. Edinburgh holds its own fortnightly meeting on a Wednesday afternoon. A representative for the Edinburgh group sits in on the weekly teleconference link and there are plans for a representative from the Monday meeting to travel to Edinburgh for the Wednesday afternoon fortnightly meeting thereby providing cross linkage between the two meetings.

A project team or steering group was established at the outset. It meets quarterly in March, June, September and December. 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 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

A close link was established at the outset with Professor Henrik Bauer and the Scandinavian Sarcoma Group. The Scandinavian model is ideally suited to the geography of Scotland. This strong link has continued to play an important part in the Scottish Managed Clinical Network. Professor Bauer gave keynote lecture at our

2005 Annual General Meeting, and has provided ongoing input and advice to our network.

Services covered - A large number of clinical services are involved most of which are locally funded. Until now only the national funded service has been for provision for endoprostheses for primary malignant bone tumours.

The services covered include the follows:

Orthopaedic Surgery  
Medical and Clinical Oncology  
Paediatric Surgery  
Paediatric Oncology  
General Surgery  
Thoracic Surgery  
Vascular Surgery  
Plastic Surgery  
Radiology  
Pathology  
Palliative Care  
Nursing and allied health professionals including occupational therapy, physiotherapy, prosthetics.

As indicated above endoprosthetics is currently the only centrally funded component of provision of sarcoma care. There are now plans in progress with National Services Division to provide central funding for the specialist management of all musculo-skeletal sarcomas.

Membership - All health professionals with an interest in sarcomas are cordially invited to attend the Annual General Meeting. There is a steering group which meets on a quarterly basis and reports back to the Annual General Meeting in November. The steering group has the following members:

T Scotland - Lead Clinician/Orthopaedic Surgeon, Aberdeen  
Dr Robin Reid - WOSCAN Lead /Pathologist, Glasgow  
Dr Michelle Ferguson - NOSCAN Lead/Oncologist, Dundee  
Dr Larry Hayward - SCAN Lead/Oncologist, Edinburgh  
Dr Fiona Cowie - Medical Oncologist, Glasgow  
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 Jill Harley - Teenagers and Young Adults Nurse Specialist, Edinburgh  
Sarcoma Patient Representative, Aberdeen  
Dr David Linden - General Practitioner, Ayrshire and Arran  
Professor Paddy O'Dwyers - Abdominal Surgeon, Glasgow  
Mr Stuart Hamilton - Plastic Surgeon, Edinburgh  
Dr Alison Mitchell - Palliative Care Specialist, Glasgow  
Dr John Mooney - Network Manager, Glasgow  
Mr Paul Welford - NOSCAN Manager, (RCAG support)

The project team appointed nine working groups to undertake tasks to improve patient management:

1. Data and Audit Collection - Mr Paul Coull, Oswestry  
Dr Jeff White, Glasgow

Dr White has almost completed the core data set for sarcoma developed in conjunction with ISD Scotland.

2. Referral guidelines and treatment protocols
  - a) Musculo-skeletal sarcomas - Lead, Mr Mike Jane, Consultant Orthopaedic Surgeon in Glasgow. Guidelines for hospital practitioners are complete and await publication on the sarcoma MCN website. Mr Jane has also been instrumental in the publication of guidelines for general practitioners in association with Janice Burrell of Cancer Strategies for the Scottish Executive.
  - b) Retro-peritoneal sarcomas - Lead, Professor Paddy O'Dwyer has completed guidelines for retro-peritoneal sarcomas and these await publication on our website.
  - c) Intra-thoracic sarcomas - Mr Alan Kirk, Thoracic Surgeon in Glasgow has provided these and they await publication on our website.
  - d) Palliative care guidelines - Dr Alison Mitchell, Specialist in Palliative Care in Glasgow has completed these guidelines and they likewise await publication on our website.
3. Nursing and allied professions - Lead, Ms Dawn Currie has met with Allied Health Professionals and they will decide on interventions by nurses and allied health professionals. This group will be involved in the publication of patient information leaflets.
4. Imaging protocols - Lead, Dr David Ritchie will provide protocols for bone and soft tissue imaging and will standardise follow-up imaging including PET scanning.
5. Pathology protocols - Lead, Professor Donald Salter, Edinburgh. Double reporting is now standard and molecular pathology is available and will be expanded.
6. Oncology and radiotherapy protocols - Lead, Dr Fiona Cowie will provide standard protocols for treatment of patients in Scotland.
7. Research and education - Lead, Mr Daniel Porter, Consultant Orthopaedic Surgeon, to promote research within the network and working in conjunction with Miss Dawn Currie to provide an education module for nurses.

8. Patient information and involvement - A patient representative works in close liaison with Ms Dawn Currie. Planned expansion of liaison with other patients throughout Scotland.

### Resources Facilities

National Network Manager (0.33 WTE)

Considerable Support from Mr Paul Welford, NOSCAN Manager

Some support for administration from WOSCAN

### 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 not yet available but is being expanded.

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

Palliative care provision throughout Scotland available at all sites.

### Clinical Quality Indicators

1. General Practitioners refer a suspected sarcoma to a sarcoma centre as early as possible.
2. All patients with a suspected sarcoma are seen at 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 MDT to establish an accurate diagnosis.
6. A definitive plan of clinical management is agreed by the MDT with patients entered into any appropriate clinical trials.
7. There is multi disciplinary surgical input eg orthopaedics, vascular, plastics, general, thoracic to any surgical treatment plan developed.
8. Full reporting of pathology for full specimen is given to MDT to allow 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 supported package that includes the following where applicable:
  - a) Follow-up imaging
  - b) Follow-up for oncology
  - c) Follow-up for surgery
  - d) Palliative medicine
  - e) Access to prosthetics
  - f) Physiotherapy
  - g) Occupational therapy
  - h) Nutrition/dietary advice
  - i) Self help groups
  - j) Psychological support

## **Section 2. Activity Report**

Specific service improvement accomplished.

1. Soft tissue sarcoma poster has been prepared, funded from endowment and distributed to General Practitioners throughout Scotland. The aim is to highlight the delay in diagnosis of soft tissue sarcomas and try and improve referral patterns.
2. Orthopaedic referral guidelines for hospital practitioners have been approved and they await publication on the website.
3. General Surgical referral guidelines for hospital practitioners have been approved and await publication on website.
4. Guidelines for head and neck sarcomas have been approved and they await publication.
5. Guidelines for thoracic metastases and primary thoracic sarcomas have been approved by the steering group and await publication.
6. Palliative care guidelines have been completed and approved and await publication on the website.
7. Scottish Bone Tumour Registry Meetings. These meetings until now have been held four times a year in the Western Infirmary in Glasgow. They provide an excellent forum for audit and education. We plan to continue holding two of these meetings a year.



The other two meetings will now be held in Edinburgh and will involve a strong research theme to encourage the development of research and publications from within the network. The first of these meetings was held in March 2007.

#### Specific service improvement in progress

1. The data set is nearing completion with a view to using ECASE as a data collection platform in the short term.
2. Radiology guidelines for bone and soft tissue sarcomas are in preparation. These will include follow-up guidelines and the place of PET scanning.
3. Radiotherapy and chemotherapy guidelines are in the process of development.
4. Website up-date is in progress. Mr Paul Welford from NOSCAN has obtained secretarial support from WOSCAN to up-date the website.
5. An osteosarcoma poster is in preparation again the plan is to distribute this to GP's to encourage and improve the diagnosis of primary malignant bone tumours.

#### Specific service improvements planned

1. The overriding need is for the firm establishment of a National database for which all data is entered. Currently all primary malignant bone tumours throughout Scotland are entered. All soft tissue sarcomas from areas other than Edinburgh are entered. Edinburgh surgeons prospectively keep their own data. We hope to employ an MDT co-ordinator in the coming months and it is envisaged that this individual may take on the role of entering data.
2. Dawn Currie, Specialist Sarcoma Nurse at the Beatson is continuing to work with our patient representative and with the nursing and allied health professional group to provide patient information leaflets on bone and soft tissue tumours. The aim is to standardise patient information throughout Scotland.
3. We continue to work with NHS QIS. We submitted our quality assurance framework and after considerable delay we heard back from NHS QIS with some suggested modification to our framework. We will meet in the near future with NHS QIS for approval of our framework.

#### Number of meetings and brief summary and content of meetings

Annual General Meeting - This meeting was held on Friday 24<sup>th</sup> November 2006. There was a strong educational input in the meeting as well as update from the

various working groups. We have tried to involve patients and on this occasion we had an 18 year old girl who had an above knee amputation who told her story. This was extremely illuminating and all present learned a great deal. The Annual General Meeting is now recognised for CME points.

The project team met in June 2006, September 2006, December 2006 and March 2007.

June 2006 - Fiona Cowie, Oncology, and David Lindon, GP, were welcomed to the group. Working groups firmed up their submissions for retro-peritoneal sarcomas and orthopaedic referral guidelines. Potential source of funding for the sarcoma poster was identified and was subsequently achieved. We decided on a new format for two of the quarterly Scottish Bone Tumour Registry Meetings. The first new format meeting was held in Edinburgh In March 2007 and we hailed as a significant success. Two meetings will continue in the conventional format in Glasgow.

15<sup>th</sup> September 2006 - The Meeting was notified that the dataset was nearly complete and it was proposed that ECASE be employed as a database. It was decided that a new MDT form should be modified to align with the dataset and that this MDT form should be formally included in the patient's notes. It was also recognised that the MDT would need formal support and this should be sought. Progress had been made with the instructional course for nurses with Sarcoma Nurse Specialist, Dawn Currie, in liaison with the University of Paisley. Further progress was made to finalisation of guidelines.

15<sup>th</sup> December 2006 - Dr David Ritchie, Consultant Radiologist, was welcomed as a radiology representative. Dr Ritchie embarked on radiology guidelines and Dr Fiona Cowie gave an undertaking to continue to pursue radiotherapy and adjuvant chemotherapy protocols. Orthopaedic referral guidelines, palliative care guidelines and general surgical guidelines were approved. Dawn Currie gave an undertaking for the nursing and allied health professional group to meet in January 2007 with nurses in the various region modifying patient information leaflets. The group discussed NSD's new definition of the sarcoma service to include all musculo-skeletal sarcomas and gave an undertaking to suggest entry and exit points into this service.

Project Team Meeting Friday 16<sup>th</sup> March 2007 - Michelle Ferguson was welcomed as NOSCAN Lead and Larry Hayward as SCAN Lead to replace Professor Elaine Rankin and Dr David Cameron respectively. It was confirmed the soft tissue sarcoma had been issued to all general practitioners. The group received an ECASE presentation from Mathew McNicol and decided this would be a useful system requiring completion of the dataset before implementation.

Dawn Currie reported that nursing and allied health professionals group met on the 7<sup>th</sup> February 2007 agreeing constitution chair and vice chair linked to the group. The group aimed to adjust leaflets and distribute across Scotland.

Dawn Currie reported that the sarcoma course would start in late 2008/2009. It was noted that the orthopaedic referral guidelines, surgical treatment protocols and palliative care guidelines were awaiting publication on the web. Dr David Ritchie circulated draft guidelines for soft tissue sarcomas and would proceed to do the same for bone tumours. Oncological and radiological protocols were in progress.

The new work plan for 2007/2008 was formulated. The new work plan would include:

- a) Osteosarcoma poster
- b) Radiotherapy guidelines
- c) Chemotherapy guidelines
- d) Radiology guidelines including follow-up and PET
- e) MDT implementation, MDT form, recruit MDT co-ordinator
- f) Implementation of ECASE
- g) Website uptake
- h) SBTR Meetings. Developed two meetings in new format.
- i) Nurse/AHB module to start September 2008
- j) Palliative care guidelines to be published
- k) Develop patient involvement

### Quality Assurance Framework

The group submitted a quality assurance framework to NHS QIS in March 2006. We have now heard back from NHS QIS and a meeting with them is imminent for accreditation of our network. We understand we will be the first Scottish cancer MCN to receive such accreditation.

### Audit Activity

Audit continues to take place by discussion of the quarterly SBTR Meetings. There continues to be a problem with Edinburgh Soft Tissue Sarcoma Data because of lack of funding. We are hopeful that we may be able to obtain an MDT co-ordinator which will facilitate data collection throughout Scotland.

### Research/Teaching Activity

The network Annual General Meeting serves as a vehicle for an annual education meeting. This is now recognised for CME points. The two quarterly SBTR Meetings held in Glasgow remain an excellent educational item both for trainees and consultants.

The first new style meeting was held in Edinburgh in March 2007 with the emphasis on papers and presentations which should help encourage publications from the network. Plans for a sarcoma study day for nurses is well underway. Modules have been approved. The sarcoma course will start in September 2008 lasting for 7 days, one day per fortnight for 14 weeks. They will probably run alternate years. The course would probably earn 20 CAP points which would stand alone or count towards a BSC in health studies.

### Plans for the year ahead

1. Meet with quality assurance Scotland to have our quality assurance framework ratified.
2. Elect a new Lead Clinician (and Vice) as the current Lead Clinician completes his three years by the Annual General Meeting 2007.
3. Tackle the new work plan listed above.

### Finance

Financial support is provided by NSS via WoSCAN for management and administrative support. This is part of an agreement that covers support for all national cancer MCNs and a financial profile will be submitted separately by NHS Greater Glasgow and Clyde.

During 07/08, taking account of the recently published HDL(2207)21: Strengthening the role of MCNs, additional funding will, as part of this agreement, also be sought to support time commitment for the MCN Lead Clinician at the level of 1PA per week.