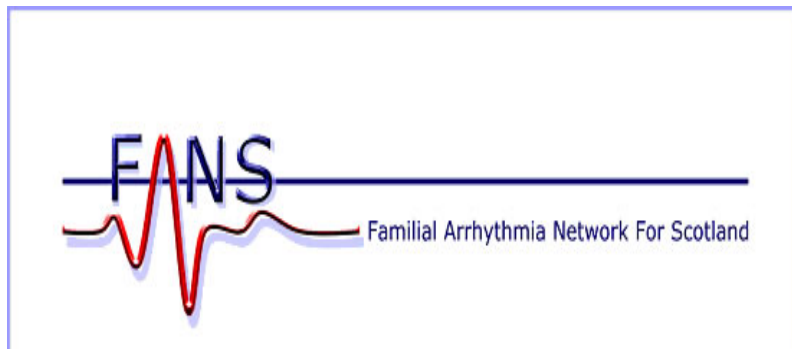


**FAMILIAL ARRHYTHMIA NETWORK IN SCOTLAND
(FANS)**

**ANNUAL REPORT TO NATIONAL SERVICES DIVISION
MAY 2010**



**Greg Fearn, Familial Arrhythmia Network Scotland (FANS) Manager
Anna Cunningham, Familial Arrhythmia Network Scotland (FANS) Administrator**

Contents	Report	Page
1.	Introduction	
1.1	Description of the Network	3
1.2	Aims and Goals	3
1.3	Service Covered	4
1.4	Membership	4
1.5	Resources and Facilities	4
2.	Activity Report	
2.1	Patients Receiving Care for Familial Arrhythmia in Scotland	5
2.2	Launch of FANS	5
2.3	FANS Website	6
2.4	Steering Group & Subgroup Meetings	6
2.5	Improving Access to FANS Services	7
2.6	Performance Against Network Objectives 2009/10	8
3.	Audit Activity & IT Issues	9
4.	Research / Teaching Activity	9
5.	Expenditure	11
6.	Objectives for 2010/11	12
	Appendix A Steering And Sub-Group Membership	13
	Appendix B Fans Organisational Structure	15

1. Introduction

1.1 Description of the Network

The Familial Arrhythmia Network for Scotland (FANS) was formally endorsed in April 2008 and the National Services Division designated NHS Tayside the host NHS Board.

FANS is a Scotland-wide service set up to improve the diagnosis and care for individuals and their families affected by familial arrhythmia. A major difficulty in the past with these conditions is that affected individuals may be seen by different healthcare professionals and this together with the difficulty in making the diagnosis, means that proper care may be delayed. The proper care of these conditions requires the involvement of many healthcare care professionals such as

- Cardiologists
- Geneticists
- Counsellors
- General Practitioners
- Specialist Nurses
- Paediatricians
- Pathologists

Lead Clinician

The Network Lead Clinician is Dr Anna Maria Choy, Consultant Cardiologist, NHS Tayside. Two sessions per week for network related matters is designated within Dr Choy's job plan. This will allow further development of the Network with financially resourced backfill being provided by the Directorate of Medicine, Single Delivery Unit, NHS Tayside.

Network Manager

The position of Network Manager has now been appointed. Mr. Gregory Fearn took up post as FANS national MCN manager on the 1st November 2009. The post is on a fixed term basis for four years.

Administrative Assistant

The position of Network Administrator has now been appointed. Miss Anna Cunningham took up post as FANS Network Administrator on 31st August 2009. The post is also on a fixed term basis for four years.

The appointment of both members of staff onto the network concludes the recruitment necessary for the network's functioning.

1.2 Aims and Goals

The Network aims to:

- Ensure patients are managed according to evidence-based, nationally agreed procedures and protocols

- Enable provision of care for familial arrhythmia in as cost effective manner as possible
- Develop and maintain a register of patients and families
- Allow audit of practice and outcomes and hence provide a basis for improving the quality of care
- Encourage multi-professional care
- Promote equity of access and service delivery at the most appropriate point of contact
- Facilitate the various strands of user involvement in service delivery and future planning of services
- Provide effective governance frameworks for all strands of clinical practice and include indicators of improved clinical effectiveness and research and development practices
- Provide a full list of clinicians with expertise/sites

1.3 Service Covered

Local teams provide care for patients close to their own homes within NHS Board areas throughout Scotland. The Managed Clinical Network aspires to enable improved access to care and specialist opinion and consistency in practice for patients requiring clinical management for Familial Arrhythmia. It is desirable that all health professionals, patients, parents, young people and children themselves have equitable and evidence-based treatment plans.

1.4 Membership

Membership has been increased and extended during 2009/10, incorporating colleagues in a greater number of disciplines. A sub-group for nurses, midwives and allied health professionals has been set up to take forward a programme of education and research. Work is also underway to set up a patient forum which will allow patients and their families to have a greater input into the Network. To this end, patient representatives and family members have been recruited to the network.

One general practitioner has withdrawn from the Network, though a new GP representative has been recruited. The new GP has a specialist interest in familial arrhythmias and undertakes sessions in cardiology at a staff grade level in PRI.

The details of professional groups involved are contained within Appendix A.

The Network's organisational structure is detailed in Appendix B.

1.5 Resources and Facilities

The appointed Network team will be based within the NHS Tayside Centre for Managed Clinical Networks (MCNs) that is housed within Kings Cross Health and Community Care Centre, Dundee.

Activity Report

2.1 Patients Receiving Care for Familial Arrhythmia in Scotland

Genetic testing for inherited arrhythmia April 2005 – March 2010 for Scotland

The table below shows the number of genetic tests carried out for Long QT, Brugada Syndrome and Arrhythmogenic Right Ventricular Cardiomyopathy in the four regional centres. These figures are from the national testing centre database at Aberdeen Royal Infirmary. The increase in numbers of tests in the 4 regions over the 5 year period reflects the increase in patients being referred for suspected familial arrhythmias. Data for actual number of patients seen is unavailable as there is no database registry to collect this data, and these patients are currently seen within general arrhythmia clinics and not specific 'FANS' clinics. Current hospital data management systems in place do not allow extraction of data regarding 'FANS' patients.

Table 1

	Aberdeen	Dundee	Edinburgh	Glasgow	Total
2005-2006	19	1	6	5	31
2006-2007	7	5	9	66	87
2007-2008	11	11	9	71	102
2008-2009	19	16	10	70	115
2009-2010	24	5	19	135	183
Total	80	38	53	347	518

2.2 Launch of FANS (3rd February 2010)

FANS was successfully launched at the Heart Disease & Stroke Cross Party Group (CPG) meeting on the 3rd February 2010 at the Scottish Parliament. The CPG is an influential working group within the Parliament which attracts a membership from MSPs across the political spectrum and other appropriate stakeholders from the NHS, other statutory bodies and voluntary agencies. It is jointly convened by the BHF and CHSS.

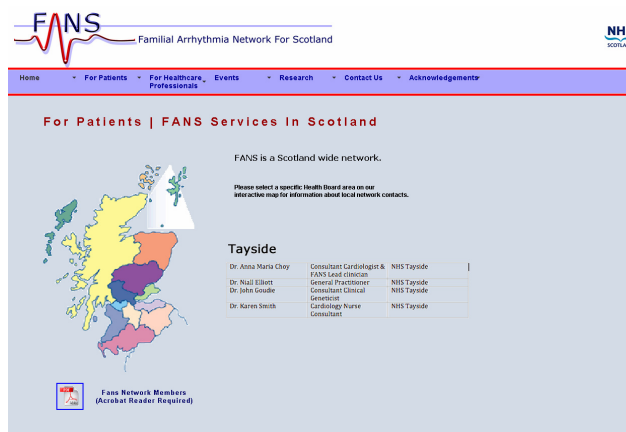
The network was launched by Ms Nicola Sturgeon MSP, Cabinet Secretary for Health & Wellbeing. Presentations from network clinicians and members of the public affected by familial arrhythmia were well received by the group. The launch was further enhanced by the completion of the FANS website (www.fans.scot.nhs.uk).



FANS network members are photographed with MSPs from the Cross Party Group

2.3 FANS Website

The FANS website (www.fans.scot.nhs.uk) was inaugurated at the FANS launch (see section 2.2). The website contains information for clinicians and members of the public alike. There are details on FANS services across Scotland, patient stories and links to other appropriate resources. There is still a great deal of site development required which will be taken forward over the coming year. In particular, the publication of pathways and protocols agreed by the FANS Steering Group. The website will play a key role in the ongoing promotion of the network.



Screenshots from the FANS website.



2.4 Steering Group & Subgroup Meetings

Quarterly meetings of the steering group were held in June, October, November and February, the latter being held immediately prior to the Network Launch Event in Edinburgh.

The Steering Group has commenced and authorised work on the following areas;

- Protocol development
- Pathway development
- Patient involvement / patient forum
- Network website / logo
- Database development

- Network launch
- Creation of a sub-group for NMAHP colleagues

Additional sub groups established to report to the FANS Steering Group are:

- Pathways & Protocols Subgroup (meeting throughout the year, Chair – Dr Paul Broadhurst, Consultant Cardiologist; NHS Grampian)
- Nursing, Midwifery and Allied Health Professionals (first meeting on the 22nd February, Chair – Dr Karen Smith, Nurse Consultant, Cardiology; NHS Tayside)
- Pathology Subgroup (first meeting 29th January, Chair – Dr Rob Ainsworth, Consultant Pathologist; NHS Greater Glasgow and Clyde)

Other subgroups in the process of being initiated are:

- Audit & Standards (first meeting on the 17th May 2010, Chaired by Professor Andrew Rankin, Consultant Cardiologist, NHS Glasgow)
- IT / Database Subgroup (to be chaired by Dr John Dean, Consultant Geneticist, NHS Grampian)
- West of Scotland subgroup (first meeting 24th May 2010)



Members of the FANS Steering Group

2.5 Improving Access to FANS Services

FANS is working closely with the four specialist centres, health boards without specialist services and regional networks to redesign local activity, job plans and clinic provision. For example FANS is liaising with SEAT re a reconfiguration of services for people with inherited cardiac conditions. Also a group has been set up to redesign services for FANS patients in the west of Scotland. The FANS Manager will be visiting key stakeholders in non-specialist centres to improve the interaction with specialist centres in terms of referrals and pathways.

Additionally FANS has started work with Forensic Pathology services (by establishing a Pathology subgroup) and the Procurator Fiscal services to embed their key role in improving communication with general practice and specialist services.

FANS has created closer links at both a regional and local level and this work is a continuing priority for 2010/11.

2.6 Performance Against Network Objectives 2009/10

Table 2

Objective	Lead Person	Annual Position
Recruit MCN manager and administrator	Head of MCNs	Both posts have now been filled.
Develop a draft Quality Assurance Framework	MCN Manager	First draft completed. To be disseminated for consultation and agreement completion of final draft.
Consolidate Network Steering Group and sub-group arrangements and work plans	Lead clinician/ MCN Manager	FANS Steering Group robustly in place. 4 subgroups initiated. 2 further subgroups to be set up early in 2010/11
Website development and launch	MCN administrator	Website now live (as of 03/02/2010).
Agreement and launch of testing protocols	Protocols sub-group lead	Five clinical protocols have now been agreed and a further three are close to being authorised by the Steering Group.
Arrangements for audit of clinical outcomes	Audit & standards sub-group lead	Sub Group Members identified, first meeting arranged for May 2010. Initial ideas for an Audit & Standards workplan have been canvassed.
Consultation and agreement for dataset, database provider and support	MCN Manager / MCN Administrator	A draft clinical dataset by the IT / Database subgroup Chair has been developed and a draft clinical audit dataset has also been produced. The network manager is also closely involved
Draft FANS Communication Strategy	MCN Manager / MCN Administrator	This has been produced. The strategy is an evolving document to reflect our approach to promoting FANS. Two newsletters have so far been published along with other materials to advocate the network. The work of FANS has been promoted at professional and patient events across Scotland.
Launch FANS	Lead clinician / MCN manager	FANS was launched successfully by the Cabinet Secretary at the Scottish Parliament on the 3 rd February 2010.
Produce service delivery report as an outcome of the service mapping exercise	Lead clinician / MCN manager.	A survey for all GPs and cardiologists in Scotland has been developed and piloted in Tayside to assess the nature of local services and professional expertise. This service mapping exercise is ongoing.
Take forward an education and research portfolio, ensuring patient inclusion in order to better target outcome developments	FANS Lead Clinician NMAHP sub-group lead / MCN administrator / MCN Manager	A national Arrhythmia Symposium was held 10 th March 2010, in the Westpark Centre, Dundee, with 102 attendees. Two research proposals have been drafted with a focus on patient perspectives of familial arrhythmia. (see section 4 for more details)

3. Audit Activity & IT Issues

The audit sub-group membership and clinical lead have been revised in light of personnel changes within the Network. The remit of the group will encompass the agreement of national datasets based on recently agreed national disease management protocols.

The Audit and Standards subgroup, under the Chairmanship of Professor Andrew Rankin will meet for the first time in May 2010. Initial audit projects have already been proposed through the Steering Group.

Datasets

It is anticipated that the group will take forward, in conjunction with colleagues at NHS National Services Division, work to establish a national audit database and disease surveillance registry. As this is likely to be a lengthy process, it is also anticipated that the group will give consideration to the implementation of short term measures for basic data collection. Already a draft clinical audit dataset has been developed and work is to begin on linking the NHS Grampian database to other regions.

National MCN Clinical Audit System

The FANS Manager is a member of the Project Board involved in producing this key element of the IT infrastructure for national MCNs. Although FANS is not one of the three initial pilot MCNs for implementation there is verbal agreement that it will be one of the MCNs to go live in the next tranche of rollout.

4. Research/Teaching Activity

March 2010

A successful Arrhythmia Symposium was held on March 10th 2010 at the Westpark Conference Centre, Dundee. The event featured speakers from across the UK and North America. Delegates were updated on the latest developments in arrhythmia management as well as given information on how to access FANS resources.

Keynote speakers included Professor Paul Dorian from St Michael's Hospital, Toronto and Dr Elijah Behr from St Georges Hospital, London. Two sessions were allocated for multi-disciplinary workshops including contributions from FANS network members Dr Paul Broadhurst, Dr Karen Smith and Adele Lewis. There was finally a moving presentation from FANS public representative Bob McConnachie whose son tragically died in 2000. The event was rounded off with panel discussion.

Research Activity

A wider research portfolio is currently under development, with the Nursing, Midwifery and Allied Health Professionals sub-group taking the lead on educational and patient-focused research issues. Links have been established with local Ethics and Research & Development committees in order to take this forward.



A research proposal to the CSO for funding is close to submission. This will look at the wider psychosocial impact of inherited cardiac conditions on individuals and their families.

It is anticipated that the planned patient forum will link into further educational events in addition to the research portfolio, ensuring that patient views and interests are strongly represented at each stage of the process.

An objective for 2010/11 is to set up a subgroup for research.

5. Financial Report (2009/10)

The financial report for the year 2009/10 is set out in Table 1.

TABLE 1
NATIONAL SERVICES
DIVISION CONTRACT
FANS MANAGED CLINICAL
NETWORK
FINANCIAL YEAR 2009/2010

	CONTRACT VALUES		12 MONTH REPORT			NOTES
	WTE	COST	BUDGET TO MAR	EXPEND TO MAR	VARIANCE TO MAR	
		£	£	£	£	
<u>STAFF COSTS</u>						
NETWORK MANAGER -Band 7	1.00	43,530	43,530	18085	-25445	Started November
ADMIN SUPPORT - Band 4	0.50	12,330	12,330	6681	-5649	Started September
LEAD CLINICIAN	0.20	31,460	31,460	5500	-25960	1 session backfill
TOTAL STAFF COSTS	1.70	£87,320	£87,320	£30,266	-£57,054	
<u>SERVICE COSTS</u>						
ACCOMODATION COSTS		875	875	875	0	
CATERING		510	510	414	-96	
PRINTING & STATIONERY		1530	1,530		-1530	
TELEPHONES/POSTAGE		510	510	12	-498	
TRAVEL		4192	4,192	519	-3673	
TRAINING		1049	1,049	180	-869	
TOTAL SERVICE COSTS		£8,666	£8,666	£2,000	-£6,666	
TOTAL COSTS	1.70	£95,986	£95,986	£32,266	-£63,720	

The major cause of the underspend for the year was due to the recruitment of both the FANS Network Manager and the FANS Network Administrator not taking place until well into the financial year. As staff costs represents over 90% of the FANS budget this was inevitable. In 2010/11 it is likely that this situation will not recur unless there is unforeseen staff turnover.

6. Objectives for 2010/11

- Distribution & Promotion of Testing Protocols
- Review and update of Testing Protocols
- Establishment of patient pathways in accordance with regional work patterns and services
- Establishment of subgroup for nurses and AHPs
- Establishment of Patient Subgroup
- Establishment of subgroup for Audit and Standards
- Establishment of an IT / Database subgroup
- Finalise the refined draft dataset to meet the requirements of database provider and support
- Consultation and agreement of audit sets
- Linkage into the NSD national Clinical Audit Database
- Develop and embed the FANS website as a central component of network's function
- Development of Draft Quality Assurance Framework
- Implementation of Communication Strategy
- Review and evaluation of website content
- Establishment of a research subgroup and implementation of research proposals

FAMILIAL ARRHYTHMIA NETWORK SCOTLAND STEERING AND SUB-GROUP MEMBERSHIP

STEERING GROUP

Membership
9 Consultant Cardiologists
1 Consultant Paediatricians
1 Consultant Pathologist
1 Senior Manager
1 National Audit Lead
4 Consultant Geneticists
2 General Practitioner
2 Patient Representative
1 Specialist Nurse
1 Nurse Consultant
TOTAL - 23 members

PATHWAYS & PROTOCOLS SUBGROUP

Remit - Define Referral pathways, taking into account the various settings and disciplines to which individuals and families present. To formulate clinical testing protocols for the familial arrhythmia syndromes.

Lead – Consultant Cardiologist

Membership
2 Consultant Cardiologists
2 Consultant Paediatricians
1 Specialist Nurse
1 Nurse Consultant
1 Consultant Geneticist
1 General Practitioner
1 Patient Representative
1 Consultant Pathologist
TOTAL - 10 members

DATABASE SUBGROUP

Remit - To determine core dataset for FANS and consider the various database options.

Lead – Consultant Geneticist

Membership
2 Consultant Cardiologists
2 Consultant Geneticist
1 National Audit Lead

TOTAL – 5 members

NURSES, MIDWIVES & ALLIED HEALTH PROFESSIONALS

Membership
3 Nurse Consultants
2 Genetic Counsellors
2 Cardiac Rehab Nurses
1 Specialist Heart Failure Nurse
1 Ward Sister
1 Senior Charge Nurse
1 Physiotherapist
TOTAL – 11 members

PATIENT INVOLVEMENT SUBGROUP

Recruitment of members for this subgroup is well advanced and an inaugural meeting will take place in early summer 2010.

PATHOLOGY SUBGROUP

Remit: to advise the group regarding genetic testing (mutations tested for, availability, and practicalities of tissue collection), to formulate and co-ordinate genetic testing protocols.

Lead – Consultant Clinical Geneticist

Membership
1 Consultant Pathology
4 Consultant Geneticists
1 Consultant Cardiologist
1 General Practitioner
TOTAL – 7 members

AUDIT AND STANDARDS SUBGROUP

Remit - to formulate standards and audit criteria for the management of the familial arrhythmia syndromes.

Lead – Consultant Cardiologist

Membership – Leads from all subgroups

FANS ORGANISATIONAL STRUCTURE

