Service Area	**Birmingham Women's NHS Foundation Trust** **Fetal Medicine Department**
Indicator name	**Annual Report for Specialised Services**
Indicator definition Include - Precise definition of what is being measured and how this will be reported e.g. % patients seen within 18 weeks - Define any numerators and denominators as appropriate - Define time periods	An Annual Report (for 08/09) detailing provision of Specialised Services (broken down into separate service areas where applicable) • Details of each the specialised service* provided inc. brief description of the service, key contacts, and staffing • Activity in each area • Details of clinical audits or monitoring carried out (or planned) • Details of SUI reporting mechanisms • Details of Patient and Public Engagement activity • Feedback on one or two key outcome measures • Development plans and challenges/issues from service perspective
Rationale for inclusion	Enhance communication, accountability and openness between Provider Trusts and Commissioners and allow better monitoring of activity and quality of patient care
Required outcomes	• Annual Report for the year 08/09 to be provided to the WMSCT by 30th Sept 09 • A meeting between WMSCT and Trust to take place to discuss the Annual Report and review progress. Meeting to be arranged annually.
Data source and collection method	Viewpoint Fetal Medicine System – Fetal Medicine Department BWNFT BWNFT hospital PAS system
Organisation responsible for data collection	BWNFT
Frequency of collection	Report to be provided annually
Baseline period / date/value if appropriate	2008/2009 Similar extensive reports are available for previous years if required
Baseline value if appropriate	Activity data: • Contracting data • Clinical activity data including key outcome measures for all procedures
Assessment of goal achievement for indicators with substantial inherent variability	Annual report covers work of Fetal Medicine Department at BWNFT All aspects detailed in the indicator definition are covered by the report
Partial completion – arrangements made for partial completion leading to stepped payments? (add detail)	No

Birmingham Women's NHS
NHS Foundation Trust

The Fetal Medicine Centre Birmingham and the West Midlands Region

Annual Report April 2008 - March 2009

Editor **Prof. M.D. Kilby**

1. Introduction

The Fetal Medicine Centre at the Birmingham Women's Hospital continues to offer local, Regional a supraregional service for prenatal diagnosis and fetal therapy.

The successful delivery of the service to patients both in South Birmingham and from other Primary Care Trusts is a credit to the hard work of our multidisciplinary team and its interaction with affiliated teams in neonatal paediatrics, surgery, cardiology and genetics.

In addition, we continue to work closely with the Newborn Networks and the Regional Specialist Services Agency to deliver a 'seamless' service. In September 2006, the Birmingham Women's Hospital was designated the Perinatal centre for West Midlands, funded by the Regional Specialist services team.

As well as Fetal Medicine services there are also several maternal medicine clinics providing specialist care (not funded by the RSSG).

Specialist Obstetric Clinics for women with pre-existing Medical Disorders: (maternal health clinics not funded by the RSSG):

1. Obstetric Renal Clinic: Dr.G Lipkin, Dr Tracey Johnston & Dr Alexander Pirie.
2. Obstetric Cardiology Clinic: Mr.Thompson & Dr Sara Thorne.
3. Obstetric Rheumatology Clinic: Dr. Gordon and Dr Tracey Johnston.
4. Obstetric Diabetic Clinic: Dr Tracey Johnston.
5. Obstetric Seizure clinic. Dr. Alexander Pirie.
6. Obstetric / Endocrinology Clinic. Dr Alexander Pirie/ Dr Shiao Chan
7. Multiples Clinic (both Monochorionic and dichorionic): Mr. H Gee and Mr. Bill Martin.

2. Midwifery Report. Veronica Donovan

During this period the department has recruited 2 new sonographers, Mrs Lida Debono and Mrs Marguerite Usher-Somers. They are both very experienced and their skills include many years experience in performing fetal echocardiography.

Mrs Debono has been working closely with Professor Kilby to set up and maintain the first trimester fetal echo screening service.

Mrs Usher- Somers has taken the lead role training other clinicians in the performance of Nuchal Translucency scans in readiness for the introduction of the combined sceening tests in 2010. This involves a close working association with the antenatal screening midwives and the community midwives.

The Fetal Medicine Midwifery team successfully run the following clinics:.

- Amniocentesis Clinic
- Midwifery /sonographer led Fetal Echocardiology Screening Service
- Pregnancy Loss Clinic

The midwives also continue to support the Fetal medicine doctors on detailed scan lists and interventions and offer support to women with a suspected or diagnosed fetal abnormality, those undergoing intervention and couples who experience pregnancy loss.

Ruth Kirchmeier, Specialist midwife has completed an audit on her extended role in the pregnancy loss clinic. She received very positive feedback from women who took part.

Helen Baker, Specialist midwife, holds a post graduate certificate in ultrasound. She has now commenced training in the performance of fetal echocardiography.

The department continues with the plan to extend the role of fetal medicine midwives by training 2 more midwives in ultrasound.

3. Patient and Public Involvement

The Fetal Medicine Centre actively involves patients in the review of new or altered patient literature. The Centre is grateful to these patients for there continued support.

The Department is well supported by families who run events, and provide personal donations to fundraise for the department. This fundraising supports accommodation, clinical and staff development programmes. On the 25th February 2009 the Fetal Medicine Department hosted an open evening for patients and staff to show appreciation to those patients and families who have generously donated money to support schemes like the creation of an additional scan room in 2008-2009.

We have worked this year with the Neonatal networks to update our neonatal surgical literature. A special thanks to Jenny Turton.

4. Summary of Clinical Governance

4.1 Audit

The Centre monitors operator competency, miscarriage rates and procedure related risks against the RCOG green top guidelines (2005) on amniocentesis and CVS. This guidance is being updated (2008/2009) and Professor Kilby is one of the co-authors. Outcomes of other procedures, such as fetoscopy, are monitored against best evidence. In addition, Professor Kilby has Chaired the First Trimester intervention audit within the West Midlands Perinatal Institute that has audited demographics, workload and outcomes of first trimester CVS. This is in anticipation of increased first trimester screening as indicated by NICE recommendation. This will be submitted for publication in the next few months. Guidelines for all Fetal Medicine procedures, including procedure related risks and benefits are updated annually. Professor Kilby has nationally been one of the co-authors of the RCOG "Greentop" Guidelines on the management of Monochorionic twin pregnancies and Amniocentesis/CVS. Professor Kilby has also been approved Chair of the NICE committee on the management of twin pregnancies.

All core audits, including outcome data for all invasive procedures, are reported in the full fetal medicine annual report.

Mr. Thompson has worked closely with the Neonatal networks in the West midlands to represent obstetric and fetal medicine views and collect data to define pressures within these services in our Region.

Dr Martin, Dr Johnston and Professor Kilby are all members of the National Executive Committee of the British Maternal Fetal Medicine Society. Dr Martin is also the senior obstetric representative for BAPM.

4.2 Training

There is a large commitment towards training within the centre. We have funding for two subspecialty trainees (SST) in Maternal Fetal Medicine in the West Midlands. We also have several Regional SpRs undergoing special modular training in obstetric ultrasound and overseas trainees on secondment from their own hospitals in Hong Kong and Ireland.

In addition, we continue to have visiting SpRs for the ATSM in Fetal Medicine and for amniocentesis training. The centre is accredited for first trimester screening.

It is now part of the training curriculum requirements for paediatric cardiology SpRs to attend 50 sessions in fetal echocardiography. The first 25 sessions are performed under the guidance of a Radiographer Advanced Practitioner after which they join the Consultant Paediatric cardiology sessions. It also forms part of the training for sub-specialty trainees in Fetal Medicine.

At the end of this year we have initiated a commitment to train our fetal medicine Midwives in ultrasound examination of the fetus. This work is on-going. The department , in collaboration with Birmingham City University , set up a post graduate taught module in fetal medicine as part of the post graduate diploma in ultrasound or as an opt in module for those with an interest in fetal medicine (eg Midwives, qualified sonographers, doctors and medical students) The first module ran for 12 weeks from March 2009. Three of our fetal medicine midwives successfully completed the module. The module received excellent feedback from student evaluation and will continue to be run annually.

4.3 Incident reporting / Serious Untoward Incidents

The Fetal Medicine Centre follows the Trust policy on the reporting of incidents and Serious Untoward Incidents(SUIs) through the Directorate and Trust risk management structure.

5. Human Resources

The service is provided on a sessional basis by a team of NHS consultants and University staff, is supported by a dedicated midwifery and administrative team and works closely with the Birmingham Women's Hospital obstetric radiology staff. The team works within the Maternity Services Directorate, and is supported by the Regional Specialized Services Agency.

See appendix for list of staff.

6. Business summary

In 2008-2009 Fetal Medicine, including the pre-pregnancy counselling service, continued to be regionally commissioned through a block contract by the West Midlands Specialized Services Agency (WMSSA).

6.1 Service developments 2008-2009

Service developments through the year have included:

- Building work to split one of the two ultrasound scan rooms. Three ultrasound rooms have been operational since October 2008 improving the efficiency of the department.
- Procurement of an ultrasound machine to run in the additional ultrasound room
- The adoption of the Fetal Medicine Centre as a Siemens Ultrasound 'Reference Centre' a collaboration which benefits the department in educational and research opportunities and allows the team to be at the forefront of trialing new fetal medicine ultrasound technologies.
- Agreement from the Specialised Services Agency to fund an additional Fetal Cardiology session for 2009-2010.
- Employment of a Specialist Radiographer in September 2008 to support the Fetal Cardiology Service and improve scan support and training in the Fetal Medicine service as a whole. Funding for this post was agreed with the WMSSA in the 2007-08.
- Employment of a Specialist Radiographer in October 2008 to co-ordinate the training of existing Trust ultrasonography staff in Nuchal Translucency scanning. This post was funded by South Birmingham PCT and is managed for Maternity Services through the Fetal Medicine Department.

6.2 Service developments 2009-2010

- In the 2008-2009 commissioning round the Specialised Services Agency agreed funding for an additional Fetal Cardiology session. This session will be implemented in 2009-2010 increasing cardiology service provision to 3 sessions per week.
- The department will be examining the feasibility of introducing 'Radio Frequency Ablation' as a more effective treatment in cases of TRAP.
- The Fetal Medicine team will be working with the Neonatal Surgery project team to implement joint Fetal Medicine / Surgical clinics. These clinics will give parents, whose baby has been diagnosed with a surgically treatable abnormality, improved access to a surgical opinion prior to delivery.

7. Activity report

7.1 Overall Clinical Activity *R Williams*

The Fetal Medicine Centre operates as the regional referral centre for the West Midlands and also treats patients from outside the West Midlands area. In area patients are funded under a block contract with the West Midlands Specialist Services Agency (SSA) and further income is received from out of area patients in line with a set tariff.

A total of 6737 procedures were completed in the Fetal Medicine Centre in 2008-2009. The majority of this activity (91%) was from within the West Midlands area patients and funded through the block contact.

The table below shows the changes in the number of procedures performed over the last three financial years.

	Examinations		
Year	2006-2007	2007-2008	2008-2009
WMSSA	5351	5976	6162
Other Region	542	467	575
Totals	**5893**	**6443**	**6737**

Table 1. Fetal Medicine Contracted Examinations 2006-2009

The Centre saw an increase in overall activity of 4.6% in 2008-2009 from the previous year.

	Attendances		Examinations		Patients	
Year	2007-2008	2008-2009	2007-2008	2008-2009	2007-2008	2008-2009
WMSSA	4025	4342	5976	6162	1927	2108
Other Region	288	322	467	575	123	139
Totals	**4313**	**4664**	**6443**	**6737**	**2050**	**2247**

Table 2. Attendances, Examinations, Patients 2007-2009

2108 patients were seen in the Fetal Medicine scan clinics, an increase on the previous year (see table 2).

The Fetal Medicine Service also covers the pre-pregnancy counselling/pregnancy loss clinics (PPCC). In 2008-2009 there were 826 attendances to the PPCC (outpatient appointments) which equates to 427 patients.

A full breakdown of Fetal Medicine examinations and PPCC attendances by PCT is shown in tables 20 and 21 in the appendices.

Fetal Medicine is a consultant lead service; Figure 1 demonstrates the expertise given to patients by individual consultants, associate specialists, specialist radiographers and midwives performing amniocentesis (excluding Pre-pregnancy clinics). The clinical care delivered by subspecialty trainees is supervised.

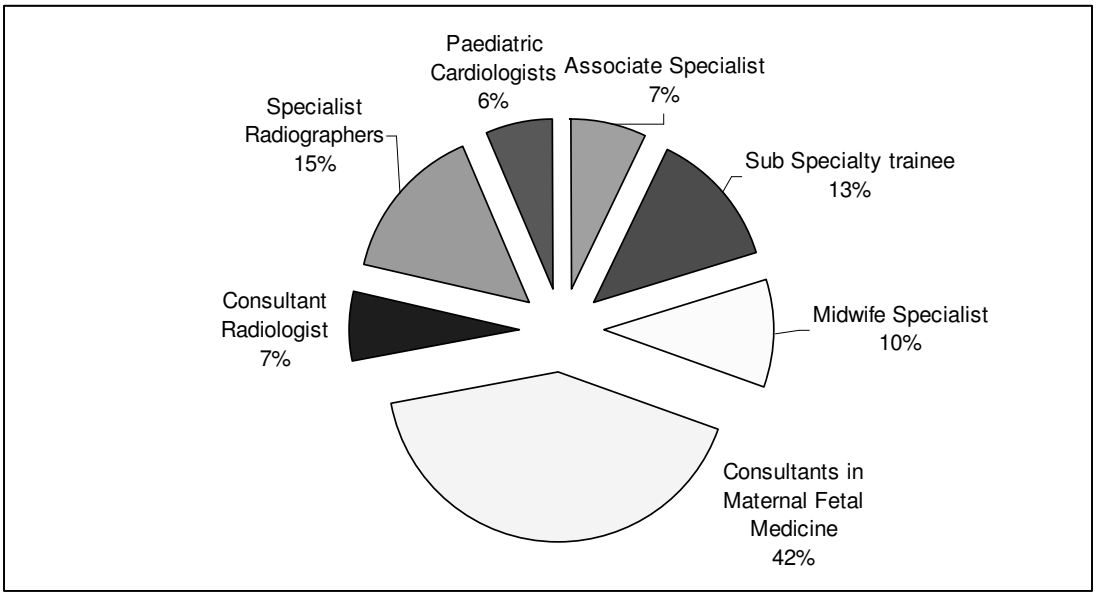

Figure 1. Total Workload By Operator Group 2008-2009

7.2 Detailed Scans *P Thompson R Williams*

3978 detailed scans were performed on 1949 patients by the Fetal Medicine consultants, radiographers and midwives; this figure includes 164 performed on patients with Rhesus disease and 50 undertaken due to a raised AFP on serum screening. 545 patients had a fetal abnormality detected on scan, Table 3 in the appendix details all the abnormalities detected at the Centre in 2008-2009. Figure 2 shows these detailed scans by operator.

	2006-2007	2007-2008	2008-2009
Detailed scan	2848	3349	3764
Raised AFP Detailed	78	82	50
Detailed Rhesus scan	174	207	164
Totals	3100	3638	3978

Table 3. Fetal Medicine detailed ultrasound scans 2006-2009

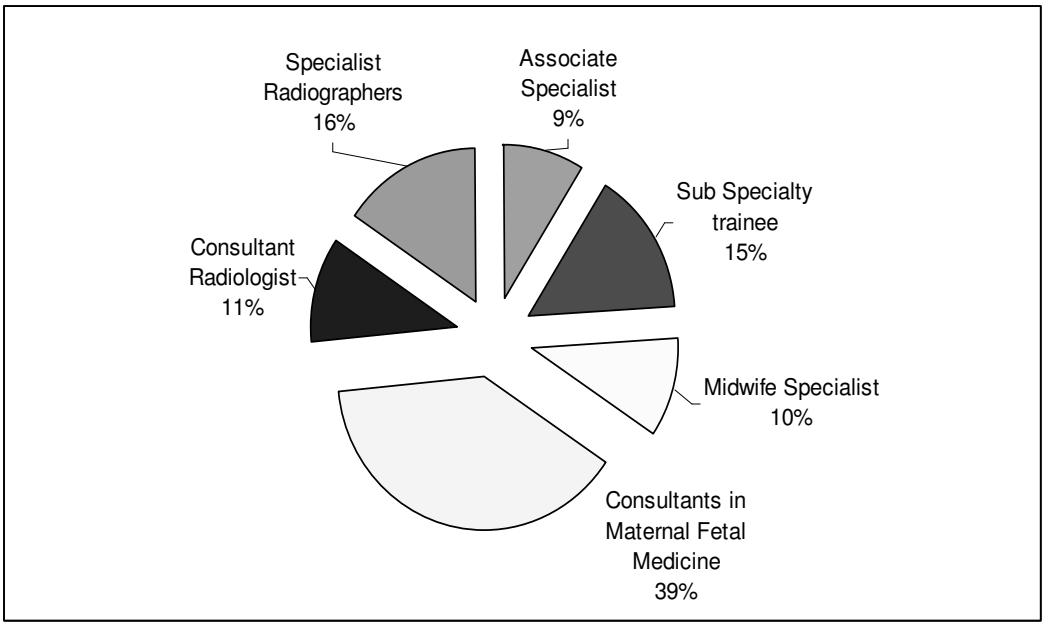

Figure 2. Detailed Scans By Operator 2008-2009

7.3 Perinatal/Paediatric Cardiology *L. Debono*

Paediatric cardiology continues to be a regional and supraregional service. The service is provided primarily by Dr. John Wright, Dr. Paul Miller and Dr Tarak Desai, who are based at Birmingham Children's Hospital and have sessional commitments here at Birmingham Women's Hospital, and also Dr Tracey Johnston-Consultant in Fetal Medicine. The service is underpinned by a Specialist Midwife and Specialist Radiographers trained in perinatal cardiology. . Much of the 'out of area' fetal echocardiology work this year has been covering sick leave for a consultant from Trent.

	2006-2007	2007-2008	2008-2009
WMSSA	856	1040	1134
OUT OF REGION	81	70	62
	937	1110	1196

Table 4 Fetal Echocardiography activity 2006-2009 by referral area.

Operator	Number of scans
Dr Paul Miller	192
Dr John Wright	122
Dr Tracey Johnson	152
Radiographer	378
Midwife	189
Other consultant	163
Total	1196

Table 5 Breakdown of examinations by Practitioners

7.4 First Trimester Chorionic Villus Sampling : *Gill Nava*

The Regional CVS Service continues to be administrated from the Fetal Medicine Centre. The number of referrals are similar to last year with a difference in these done for maternal age due to increasing popularity of private first trimester screening. The CVS performed due to an increased risk from first trimester screening are included in the fetal medicine/ placental biopsy section.

Referrals to the service are counselled, mainly by telephone, by the clinical midwife specialists or are referred directly by the Clinical Genetics team. The chorionic villus sampling (CVS) is performed at two main centres in the West Midlands, either at Birmingham Women's or Heartland's Hospital depending on the referring PCT.

INDICATION FOR CVS	2006-2007	2006-2007	2008-2009
Maternal age > 35 years	37	37	25*
Clinical Genetics	73*	73*	52
Previous Chromosome abn.	15	15	30
Previous Fetal abn. (structural)	3	3	0
Other	10	10	1
Total CVS performed	138	138	108

Table 6 BWH Indications for CVS 2006-2009
*includes 1 twin pregnancy

Of the 108 CVS's performed, 23% were for the indication of increased maternal age of 37 years or over. 48.% were referrals from the Clinical Genetics service and 28% were for a previous chromosome anomaly. 1 was performed for maternal anxiety.
In 1 CVS performed for a previous chromosomal anomaly, no result was obtained as the tissue sampled was maternal decidua.

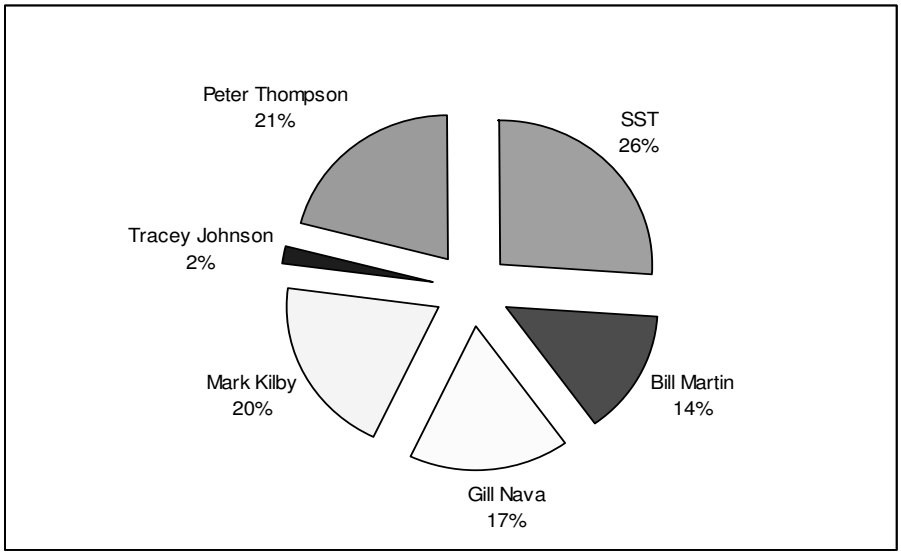

Figure 3. CVS by operator 2008-2009

Out of the 108 CVS performed there were 16(14.8%) chromosome and genetic anomalies detected including 1 mosaic result.
There were 14 in the clinical genetics group and 1 in the non clinical genetics group.

Abnormality	Number	Outcome
Trisomy 21	1	TOP

Table 7. Abnormalities detected on CVS – non Clinical Genetics patients-

Abnormality	Number	Outcome
Unbalanced translocation	5	4 TOP 1 LB
Balanced translocation	5	3 LB 2unknown
Duchenne Muscular dystrophy	1	1 TOP
Cystic Fibrosis	1	1 TOP
Sickle disease	1	TOP
Mosaic Result Zellwegers	1 1	1 normal on amnio TOP

Table 8. Abnormalities detected on first trimester CVS – Clinical Genetics Patients

OUTCOME AFTER CVS	2006-2007	2007-2008	2008-2009
TOP for abnormality	12.3	15.2	8.34%
TOP for social reasons	1.5	1.5	1.0%
Miscarriage	2.9	3.0	0%
NND	0.7	0	0%
IUD/SB	0.7	0	0%
Liveborn (normal)	67.4%	80%	47%

Table 9. Outcome information for first trimester CVS (%)

There were 61/108 known outcomes at the time of the annual report 2009 Abnormal outcome is more likely to be represented as miscarriage and termination unless fully reported by patients. Some patients as of yet had not delivered.

Of the total 108 CVS performed 0 miscarriages were reported – giving a miscarriage rate of 0% assuming all have been reported.

These figures are again to be collated into the Regional Audit of CVS services (Chaired by Prof.Kilby. http://www.pi.nhs.uk/cvs/.)

7.5 Amniocentesis : *Veronica Donovan*

The amniocentesis service continues to be provided by a group of specialist staff. All operators are trained to the basic standard as recommended by the RCOG. The department provides a training service for SpR's rotating through the hospital. During this period two trainees have completed their amniocentesis training.

The Fetal Medicine Centre holds an annual amniocentesis workshop open to doctors and midwives. This provides theoretical instruction and hands on training using artificial models.

A total of 285 amniocenteses were performed during the current year. This includes 13 sets of twins, twins are recorded as a single procedure. Amniocentesis in the case of twin to twin transfusion syndrome are recorded in a separate section of this document. Figure 4 gives a breakdown of amniocentesis by indication. Figure 5 shows the breakdown by operator (or supervisor).

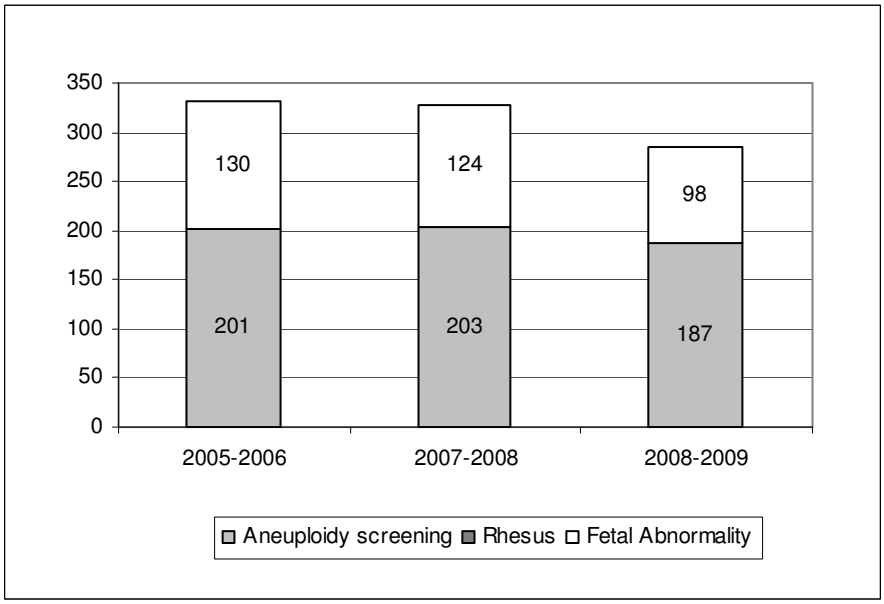

Figure 4. Total number of amniocentesis performed per year 2005-2009

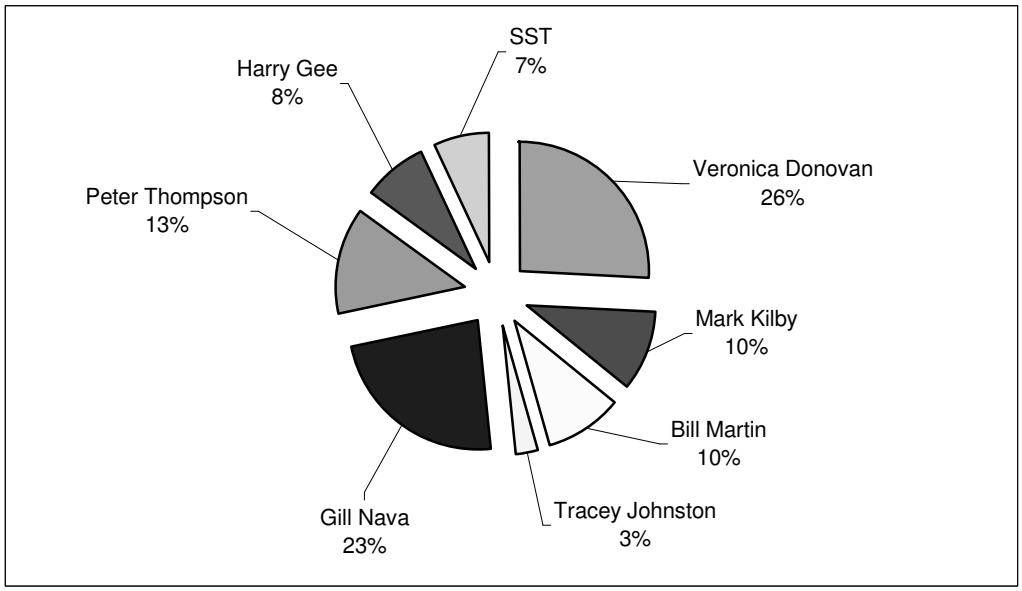

Figure 5. Amniocentesis by operator 2008-2009

7.5.1 Amniocentesis for Aneuploidy

There were 187 amniocentesis performed for screening for aneuploidy. The main indications are illustrated in Figure 6 compared with the two previous years. (NB figures include referrals from other regional hospitals).

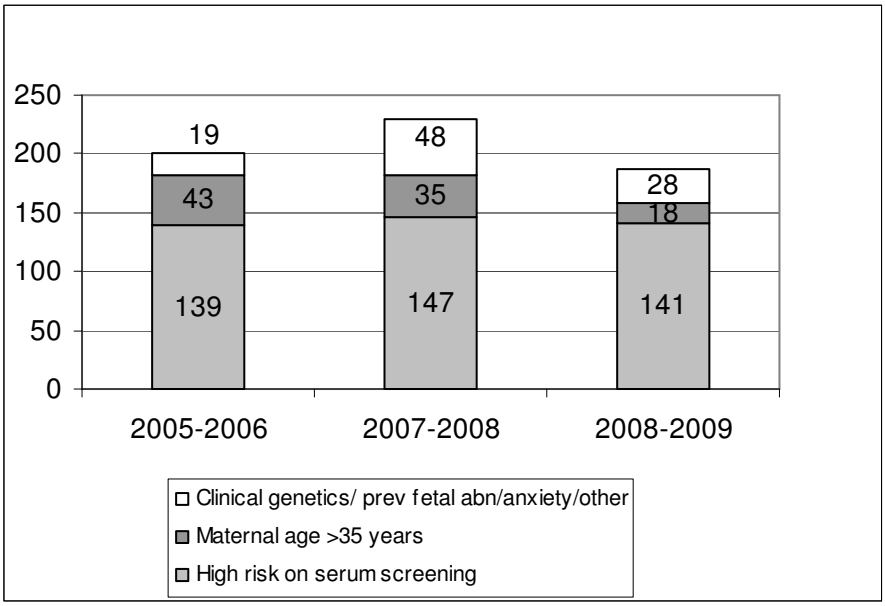

Figure 6. Indications for amniocentesis for aneuploidy screening 2005-2009
*missing data 2006-2007

Indication	Number	Aneuploidy /genetic condition Detected	Outcome
High risk serum screening result / NT	141 (8 from 1st trimester screening)	Trisomy 21x5 Balanced inversion Y chromosome Variation short arm chromosome 15 Mosaic trisomy 15	2LB, 3 TOP LB LB LB
Maternal Age >37 years	18 (8 outside referrals /10BWH)	Trisomy 21	TOP
Previous fetal abnormality/ maternal anxiety/ clinical Genetics / other	28	1 cystic fibrosis (normal karyotype) Balanced translocation	LB LB
Total (inc. 10 sets of twins)	187		

Table 10. Aneuploidy detected by indication (for screening amniocentesis)

7.5.2 Amniocentesis for karyotyping in fetal abnormality/suspected fetal abnormality.

98 amniocentesis were performed for karyotyping on patients with a fetal abnormality or a suspected fetal abnormality following detailed scan, including 8 twin pregnancies. The chromosome abnormalities detected and pregnancy outcome are detailed in table 11.

Abnormality	Number	Outcome
Trisomy 21	6	TOP X 5 IUD X1 at 24 weeks
Trisomy 13	3	TOP X 3
Trisomy 18	6	TOP X 4, SBx1, IUD X 1 at 34 weeks
Deletions	2	1 UK 1LB
Monosomy X	1	TOP
Tripoloidy	1	TOP
Other	1	LB
Total	20	

Table 11. Chromosome abnormalities detected on amniocentesis for fetal abnormality.

7.5.3 Outcomes after amniocentesis

Outcome	Amnio. for fetal abnormality	Amnio. for screening	Total births from Amnio.
Live births	68	180	248
TOP	20	4	24
Miscarriage		1	1
Still births/IUD	6	0	6
Unknown outcome	12	6	18

Table 12. Pregnancy outcome after amniocentesis for fetal karyotyping (13 twin pregnancies counted as 2 outcomes)
Nb: Of the 18 missing outcomes there are 2 sets of twins and all pregnancies are over 36 completed weeks of gestation.

7.5.4 Amniocentesis for Maternal Age

A total of 18 amniocentesis were performed for maternal age. 8 were outside referrals and 10 were BWH patients. The ages ranged between 35 and 47 years. All had been appropriately counselled with regard to the risks. One karyotype abnormality was detected in a 41 year old woman (Trisomy 21) this pregnancy was terminated. There were no other fetal losses.

8. Fetal Blood Sampling: *Ellen Knox / Bill Martin*

A total of 46 fetal blood samples were performed in 2008 to 2009. Eleven of these were in association with late termination of pregnancy; one was taken during a selective reduction for fetal abnormality. There were 4 performed for investigation of possible anaemia, 2 were shown to be due to infection with parvovirus B19 and 2 with rhesus disease.

In 31 cases, fetal blood sampling was performed for rapid karyotyping when an associated fetal anomaly was detected (after 20 weeks). In 7 of these the test was performed as part of the investigation of fetuses presenting with hydrops fetalis. In 4 as mentioned above, it was used to assess fetal anaemia. The karyotype was normal in 26, abnormal in 3, (uncertain in 13)

The indications for fetal blood samples compared with previous years are shown in figure 7.

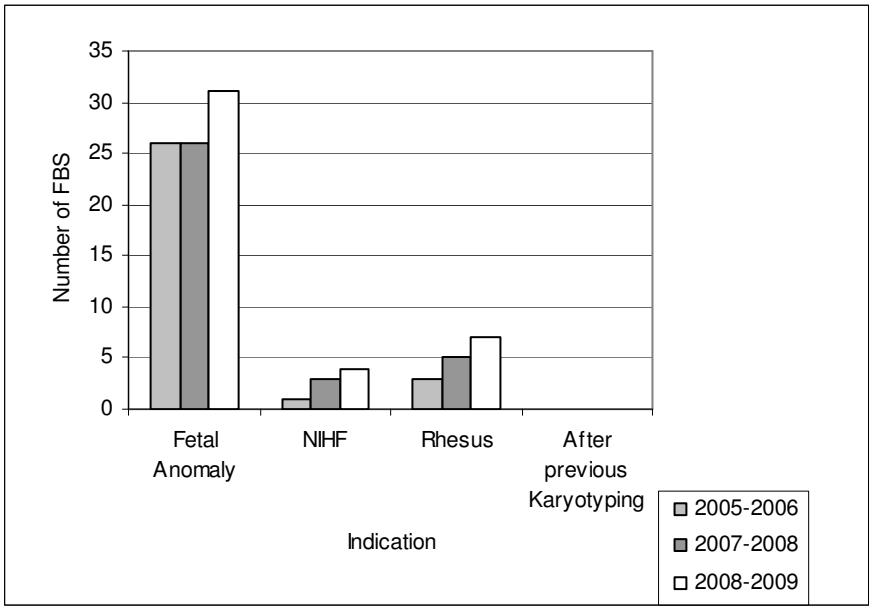

Figure 7 Indication for fetal blood sample 2007-2009* missing data 06/07

Fetal blood sampling was obtained from the intrahepatic vein in 16 cases, the umbilical cord in 17 cases, cardiac in 13.

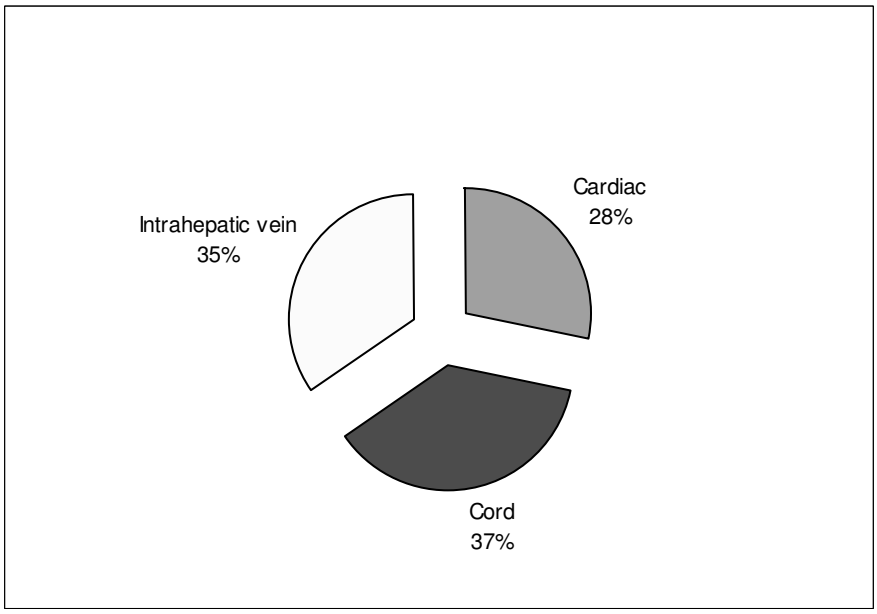

Figure 8 Site of Sampling 2008-2009

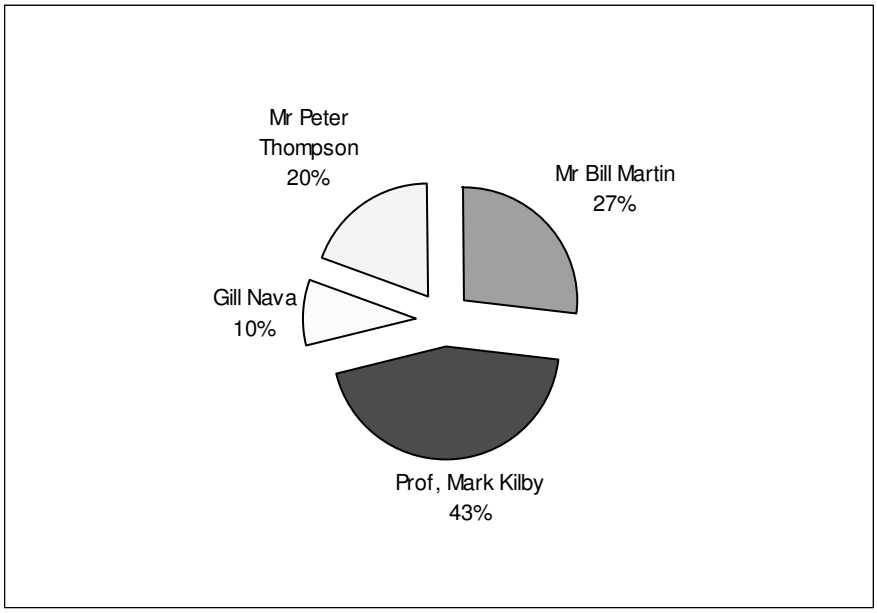

Figure 9 Fetal Blood Sampling by Operator 2008-2009

8.1. In-utero blood transfusions: *S Pretlove*

In the year April 2008 to March 2009, a total of 29 in-utero transfusions were performed in our centre. There has been a progressive reduction in the number of patients requiring fetal transfusion, in line with improved prenatal and postnatal prophylaxis. They involved 15 singleton pregnancies.

Among these 15 patients, four of them were booked cases in Birmingham Women's Hospital whereas eleven of them were referred from other hospitals.

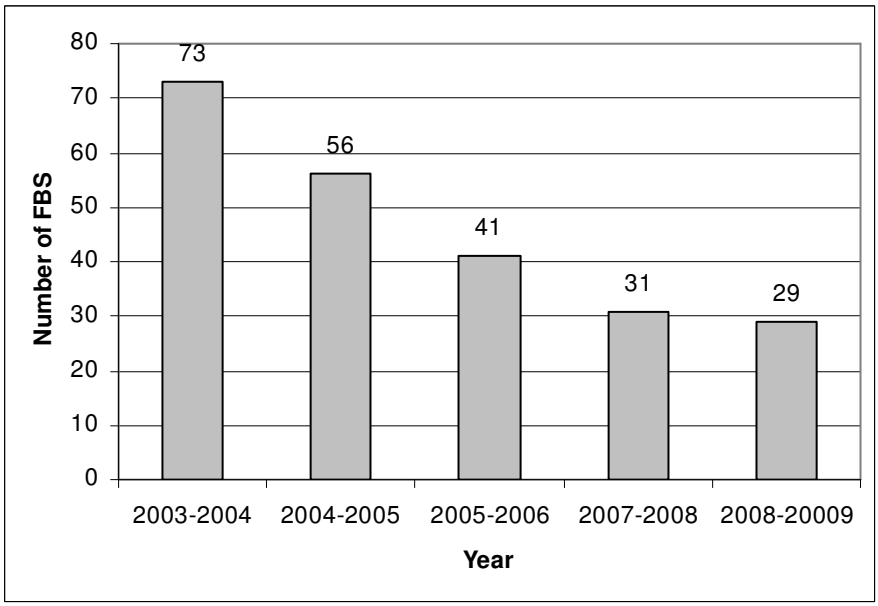

Figure 10. Number of in utero transfusions (FBT) performed 2003-2009

There is a significant down trend in referrals of patients that require in-utero transfusion. This is in keeping with the successful implementation of anti-D prophylaxis within the West Midlands.

6 pregnancies were complicated by maternal red cell alloimmunisation as a cause of fetal anaemia. 8 pregnancy was complicated by parvovirus. One pregnancy loss involved a fetus with trisomy 21 that developed transient abnormal myelopoiesis as an extremely rare cause of fetal anaemia. The other was a fetus severely affected

with parvovirus with an intial haemoglobin of 1.4g/Dl who sadly died the day after the in-utero transfusion.

Fetal intravascular transfusions was performed by the intrahepatic vein in 25 (86.2%) cases, the umbilical cord in 4 (13.8%). No transfusions were performed by the intraperitoneal route.

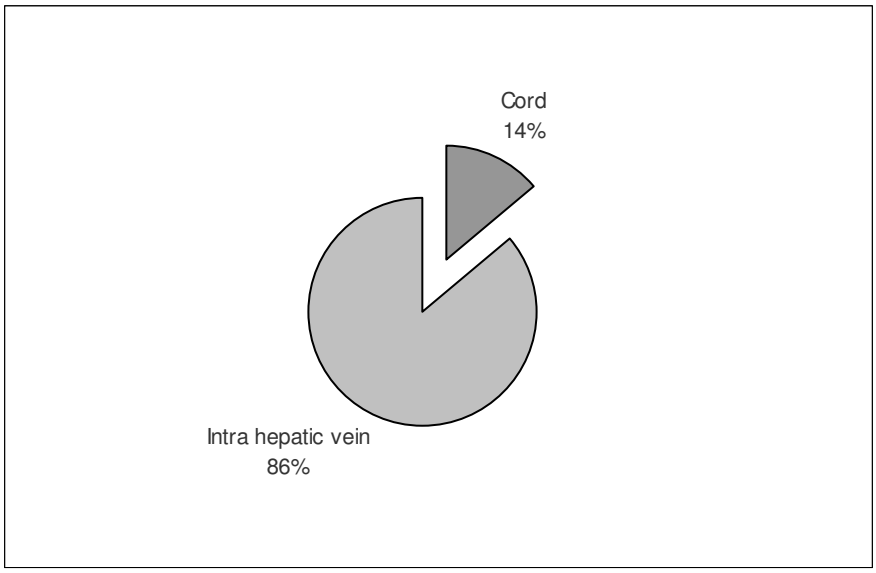

Figure 11. Site of Transfusion 2008-2009

The operators performing these transfusions are shown in Figure 12

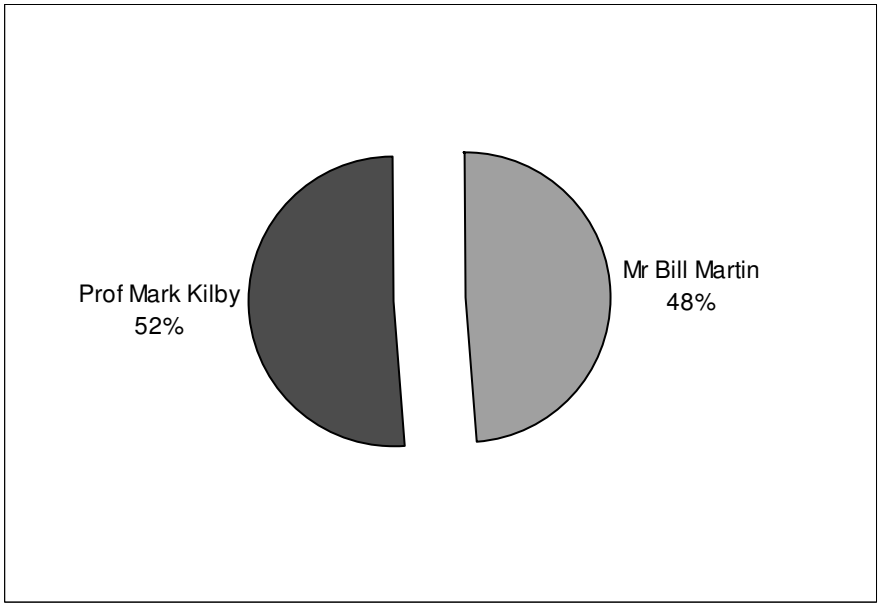

Figure 12. Transfusion by Operator 2008-2009

7.8 Second trimester (>14 weeks) placental biopsy / placental biopsy for fetal abnormality *G Nava*

There were eighty two chorionic villus samplings performed because of abnormalities detected on ultrasound and for an increased risk from nuchal translucency screening and first trimester biochemistry screening

Indication and Gestation	No.	Chromosome Result	Outcome
Increased risk from first trimester screening	30*	4 Trisomy 21 1 Trisomy 18 1 no result from CVS - amnio showed Truism 13	3 TOP, 1 TOP 1 TOP
Cystic Hygroma / increased nuchal translucency	26	3 Trisomy 21 3 Trisomy 18 2x0 1 ?? 2 triploidy	3 TOP 3 TOP 1TOP 1UNK UNK 1 top, 1 missed miscarriage prior to CVS
Hydrops	1	Normal	1 TOP
Structural ultrasound anomalies	25	1 Trisomy 13 1 Trisomy 18 1Unbalanced Translocation 21 normal chromosome 1 No result due to maternal contamination	1 TOP 1TOP Miscarriage 8 TOP 2 IUD 1 SB
Totals	82		

Table 13 Indications and outcomes placental biopsy

There were similar numbers of CVS performed for increased risk from screening (37%). Cystic Hygroma increased nuchal translucency and structural anomalies (30%)

The structural anomaly group included 9 performed for megacystis/bladder neck obstruction, 6 for exomphalos and 3 for multiple anomalies.

Of the 82 CVS performed there were 19(23%) chromosome anomalies detected.

Overall 1 procedure (1-2%) was associated with miscarriage , 4 (5%) with stillbirth or intra uterine death.

The miscarriage occurred in a fetus with an increased nuchal translucency and exomphalous and the karyotype showed an unbalanced translocation.

2 CVS were performed where inadequate samples were obtained. 1 CVS was performed for an increased risk from first trimester screening, after 2 attempts insufficient samples were obtained for analysis. A later amniocentesis showed trisomy 13. The second CVS was also done for multiple anomalies and the sample showed maternal cell contamination, an amniocentesis was performed at the same time and showed normal chromosomes.

7.9 Management of Twin-twin transfusion syndrome (TTTS) *M Kilby*

Between 1st April 2008 and 31st March 2009, there were 46 pregnancies with TTTS considered for fetoscopic laser ablation (an increase of 95%- see figure -) Forty five were monochorionic twins and a single set of dichorionic triplets .40 pregnancies had Quintero stage III or greater.(84.8% Stage III AND 2.1% stage IV) There was 1 pregnancy complicated by stage I disease(2.1%) and 5 complicated by stage II disease(11%) These pregnancies were all offered and accepted fetoscopic laser ablation (FLA).

The principle operator was MK in 34/46 (74%) and WM in 12/46(26%).
In 61% of pregnancies a selective technique was utilised. A median of 6.5 AVA were coagulated using a Diode laser (range4-9 AVA)

The median gestational age at presentation and operation was 21.4 weeks (95% CI 20.1 – 21.9 wks). Of those that had double fetal losses, this occurred at a range of

between 1-3 weeks post-FLA. All these were miscarriages associated with bleeding and/or PPROM (rather than immediate double IUD).

Following examination of the cohort in total, the overall fetal survival post-FLA 66.6% (62 of 93 fetuses). Of these, there were single survivors in 52% of pregnancies. In 41.3 % (19/46) of pregnancies there were two survivors and in 6.7% of pregnancies there was a double pregnancy loss (all through miscarriage).

Thus, in 93.3 % of pregnancies there was at least one survivor.

The median prolongation of pregnancy in weeks was 13 weeks (95%CI 10.4 -13.6 wks.)

The median gestation of delivery (of pregnancies with at least one survivor) was 34 wks (95% CI 32.7 - 34.3wks). This was with a policy of 'elective delivery' between 34-36 weeks, usually by caesarean section.

This data can be added to the total cohort collected since October 2004 (when FLA was initiated) and March 2009.

Since October 2004, we have provided a supraregional service for this fetal therapy. In a 4.5 year period, 119 MC twin pregnancies complicated by severe TTTS were assessed and considered to warrant FLA (that have completed to delivery).

The maternal age of the cohort was 35 (median; 95%CI 25.4-36.8) yrs. And the gestational (GA) at diagnosis was 20 (95%CI 19.5-20.6) wks.

Quintero staging indicated that 3.4% were stage II, 87.4% stage III and 9.2% stage IV disease. All patients underwent FLA with regional anaesthesia using standard fetoscopic technique performed by 2 operators.

In 84% of cases, operative amnioinfusion was utilized. Planned selective procedure was used and 5 (range 4-9) AVA were coagulated using a Diode laser. Therapeutic amniodrainage was performed at the end of the procedure (1600ml [95%CI 900-4600]). The total survival of this cohort was 62.6% and in 84% of pregnancies there were one or two fetal survivors.

There was two IUD in 15.9%, 1 live birth (LB) in 42.8% and two livebirth in 42.6% of cases.

The GA at delivery (LB) was 33 (95%CI 31.8 – 32.8) wks. Elective delivery was advised between 34-36 wks.

In 3 fetuses (2% of post-FLA survivors) there was ventriculomegaly noted post-FLA (in 2 TOP performed). In one baby, the pregnancy continued and the ventriculomegaly was 'minimal' on neonatal cranial ultrasound. In 6 babies (4%) there was MRI/US evidence of "CNS abnormality" in neonatal period (in three of these babies this was a severe anomaly with a high predicted risk of cerebral palsy development).

These data indicate that outcomes in this large single centre cohort are similar to internationally published data.

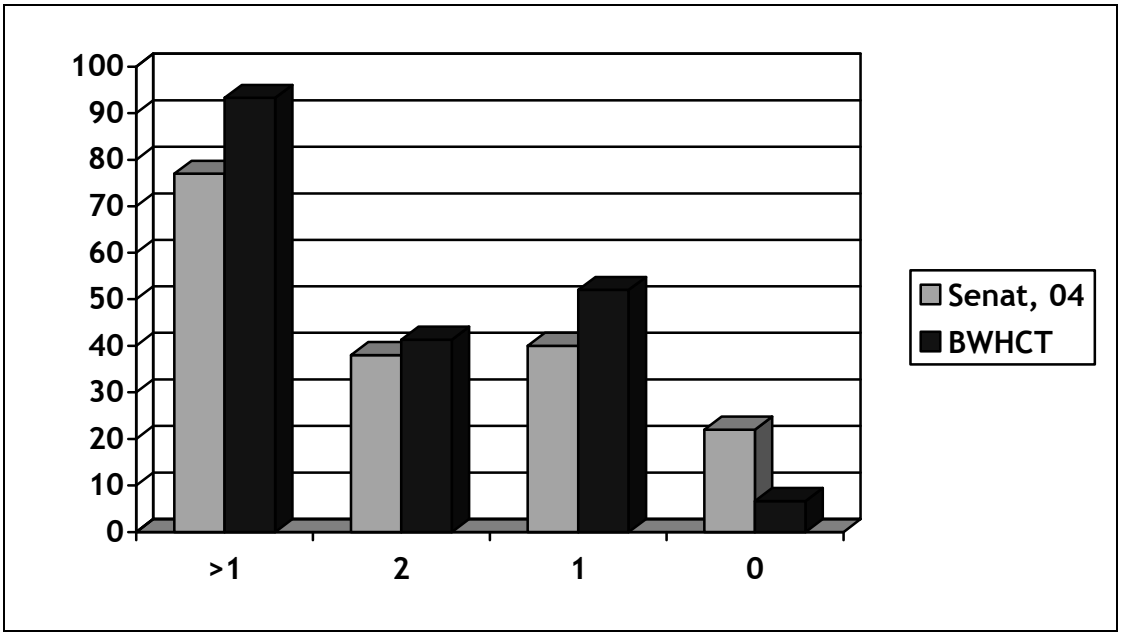

Figure. 13 Outcomes for laser ablation: April 2008- March 2009.

8.0 Other invasive fetal therapy: *Sam Pretlove and Bill Martin*

During the course of 2008-2009 there were a total of 22 procedures performed on 17 patients as detailed below.

Seven women required amnio-drainage during pregnancy with a total of ten amnio-drainages performed. Three women had pregnancies complicated by mild twin twin transfusion syndrome. The drainage was required twice in one case and once in the other two cases. In two cases there was marked polyhydramnios of unknown cause. In one the cause remains unknown; in the other diabetes insipidus was the cause of the excessive fetal urine output. In both cases two amniodrainages were required. In one case there was duodenal atresia with normal chromosomes that failed to respond to medical amnioreduction with sulindac. In the final case amniodrainage was performed to prevent preterm labour in a baby with multiple congenital abnormalities. The karyotype was subsequently found to be abnormal (trisomy 18) and the pregnancy was terminated.

There were three cases of lower urinary tract outflow obstruction (LUTO). In all cases the prognosis was very poor. Two had bladder drainage, the urinary analytes showed a poor prognosis and one opted for termination. The other was sent back to referring hospital, outcome currently unknown. In one a vesicoamniotic shunt was inserted after recruitment to PLUTO, a randomised trial of percutaneous vesico-amniotic shunting. Sadly the baby died soon after birth because of pulmonary hypoplasia.

In one case holoprosencephaly was diagnosed. The couple wanted to continue with the pregnancy but given the very poor prognosis wanted to avoid a Caesarean delivery. Late in pregnancy there was massive hydrocephalus, therefore to aid delivery fluid was drained from the cranium. A vaginal delivery was achieved and the baby was stillborn.

When a pregnancy is affected by pleural effusions, the diagnosis can be aided by needle aspiration and if the fluid re-accumulates then permanent pleuroamniotic shunting can be carried out. One fetuses underwent pleural drainage alone, and in three a shunt was inserted (one of these had pleural drainage and then a shunt inserted subsequently). Two of the four were born in good condition and continue to

do well. The remaining two the outcome was one livebirth with right pleural effusion and sadly one stillbirth at 33 weeks.

One patient was recruited to AMIPROM and multicentre trial to assess the use of amnioinfusion where there is premature rupture of membranes between 16 and 24 weeks. This latter complication often leads to pulmonary hypoplasia and neonatal death. 2 amnioinfusions were carried out. The patient ultimately went on to deliver very prematurely and the baby died soon after birth.

In the final case there was TRAP sequence. This was treated with intrafetal laser at 16 weeks. This unfortunately ended in IUD at 18weeks.

During the course of 2008-2009 there were a total of 25 procedures performed on 20 patients as detailed below. These procedures were various percutaneous treatments.

1. Mild twin to twin transfusion syndrome: Eight women required amniodrainage during pregnancy with a total of 10 amniodrainages performed in total. Four women had pregnancies complicated by mild twin-twin transfusion syndrome (one in a set of triplets)(Stage 1). Two of the women only needed one drainage and the other two had the drainage repeated a second time.

2. Complications of monochorionic twining: Three further sets of twins had amniodrainage but for different reasons. One set was complicated by TRAP sequence but with a haemodynamically stable pump twin with polyhydramnios. In another set, both twins had fetal anomalies and sulindac failed to control the polyhydramnios and amniodrainage was opted for. In the final set, one twin had findings of ascites and polyhydramnios which were thought to be secondary to a viral infection but this was never confirmed. The ascites was also drained and only one amniodrainage was required.

3. Congenital malformations: A singleton with a congenital diaphragmatic hernia also required an amniodrainage for uncontrollable polyhydramnios.

Babies with a diagnosis of lower urinary tract obstruction were recruited to RCT of Percutaneous vesicoamniotic shunting for lower urinary tract obstruction (PLUTO). Three fetuses were randomized to shunting. One baby is alive and doing well post-natally, one pregnancy is still on going and in one fetus the shunt only drained initially. In the latter case, the baby had a bradycardia post-shunting and the parents opted for termination of the pregnancy.

Thoracocentesis may be a useful adjuvant to diagnosis and treatment of pleural effusions. Post-aspiration and investigation, if the fluid re-accumulates then permanent pleuro-amniotic shunting may be performed. In 2007-2008 5 fetuses required pleural drainage and in 4 thoraco-amniotic shunting was performed. One baby was hydropic before shunt insertion and sadly died shortly after the procedure. Two women had a second shunt insertion when a shunt that had been working well appeared to become displaced. One woman ruptured her membranes prematurely at 25 weeks following placement of the second shunt but continued with the pregnancy. Sadly the baby died following delivery due to pulmonary hypoplasia secondary to the pleural effusion. In the two babies where shunting was not performed one was delivered at 34 weeks gestation as the second fetus in a twin pregnancy and did well. The other baby had a large intrathoracic cyst and although this had been aspirated the baby died shortly after birth at 29 weeks.

One fetus had presented with a large sacrococcygeal teratoma with a significant cystic component. Drainage of the mass was performed prior to delivery.

4. Direct cardioversion for incessant tachyarrthymia. One baby had direct intra-uterine 'medical' cardioversion (i.e. fetal intravenous adenosine cardioversion) following failure of conventional (transplacental therapy) drug therapy to control a supra-ventricular tachycardia. The baby was hydropic before the procedure and unfortunately died prior to birth.

9 Pre-pregnancy Counselling / Pregnancy Loss Clinic (PPCC)

Within the Fetal Medicine Department, the PPCC continues to provide a regional service for couples who have experience of the following:

- Recurrent first trimester miscarriages
- Second trimester miscarriages
- Stillbirth or neonatal death.
- Fetal anomaly
- Pre-existing maternal disease
- Previous severe pre-eclampsia

The aims of the clinic are:

- To carry out relevant investigations to identify any causes of pregnancy loss.
- To suggest any treatment which might be beneficial in a subsequent pregnancy.
- To make an individualized plan of care, treatment and support for a subsequent pregnancy.
- To provide support and counselling following pregnancy loss and in any subsequent pregnancy.
- To provide pre-pregnancy counselling for women with a maternal disease.

The PPCC continues to be the regional centre for the investigation of women who have experienced severe pre-eclampsia in a previous pregnancy, in collaboration with APEC.

Midwifery Support

Ruth Kirchmeier Senior Specialist Midwife in Fetal Medicine sees her own caseload of pregnancy loss patients for review of investigations and to make a plan of care for a subsequent pregnancy. She also provides individual, short term bereavement counselling for women/couples who have experienced pregnancy loss.

Midwifery input and bereavement support are provided by the team of Specialist Midwives in Fetal Medicine, Ruth Kirchmeier, Gill Jongman, Brenda Bolger, Nia Carnevale, Jane Meredith and Maria Masoud.

The service is predominantly midwifery led, as the team of midwives have developed considerable experience and expertise in working with women/couples who have had recent pregnancy losses and in providing support in subsequent highly anxious pregnancies.
Invaluable to the smooth running of the clinic, secretarial support is provided by Vicki Morrison-Thomas.

9.1 Miscarriage Support group

In May 2003, a Miscarriage Support Group was set up in conjunction with the Miscarriage Association, and continues to be held monthly at the Women's Hospital. The group is coordinated by Alison Noakes, a previous patient of the clinic. Ruth Kirchmeier Specialist Midwife and Caroline Brannigan, Specialist Nurse from EPAU, provide professional support. Patients seem to greatly appreciate the opportunity to be able to discuss their experiences informally with others who have been through similar events.

9.2 PPCC activity

9.2.1 Overall numbers seen

Table 14 demonstrates the numbers of women seen in the clinic from April 2008 to March 2009, differentiated according to type of appointment.

Primary Midwife Visit	Consultant review	Pregnancy support	Total number seen
366	253	411	1030

Table 14. Attendances 2008-2009

9.2.2 Source of referral

Figure 14 demonstrates the distribution of referral according to their source for women coming for their appointment with the specialist midwives and attending the Consultant Clinic.

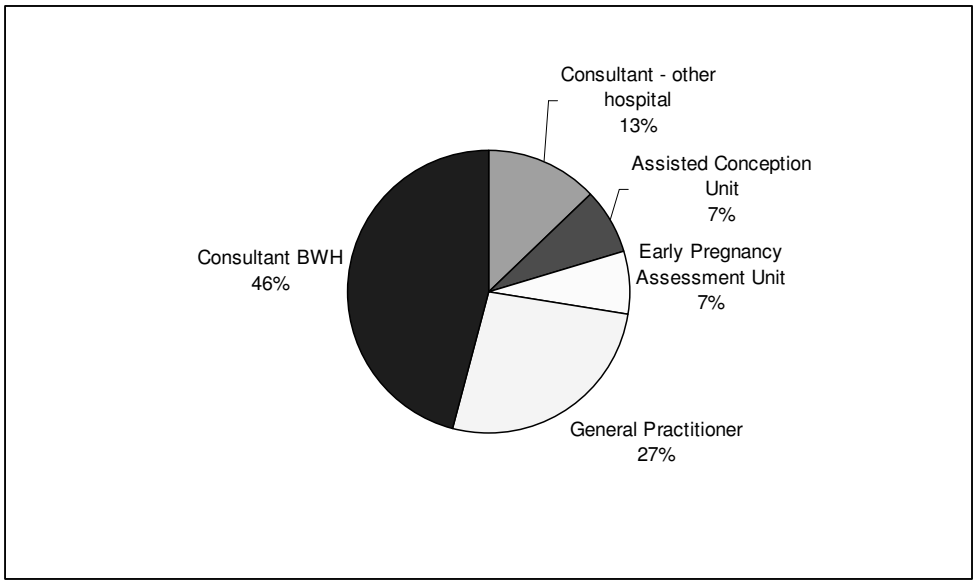

Figure 14. Referral by source PPCC

9.2.3 Type of pregnancy loss

Figure 15 demonstrates a breakdown of the numbers of women experiencing the different types of pregnancy loss.

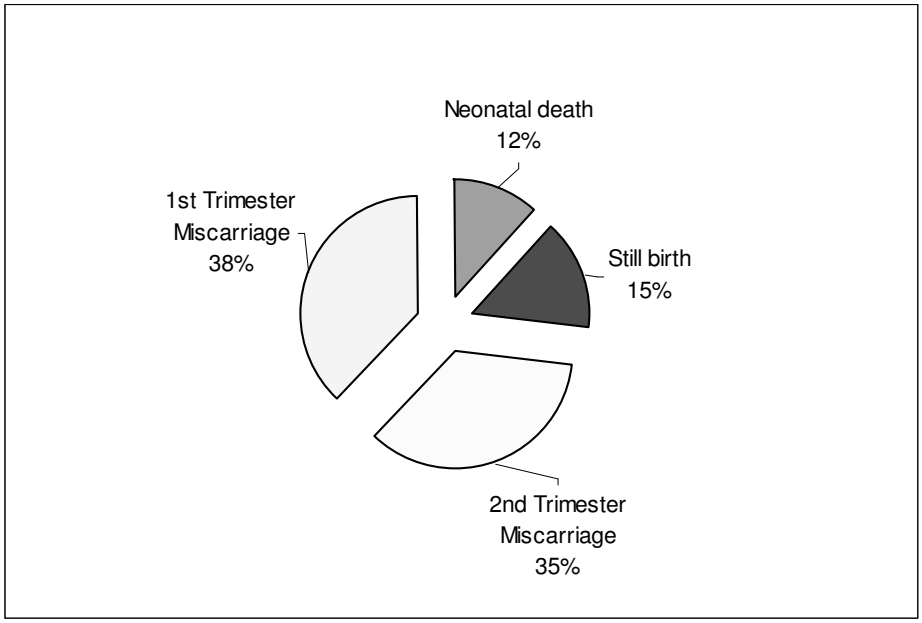

Figure 15. Type of pregnancy loss

9.2.4 Reason for referral

Table 15 demonstrates the distribution of reason for referral for those women attending their first visit with the specialist midwife and attending the Consultant Clinic. There will be a number of women who will fall into more than one category of referral.

Reason for referral	Number of women (%)
Pregnancy loss (recurrent)	494(48)
Maternal disease	320(31)
Fetal anomaly	216(21)

Table 15. Reason for referral to PPCC (first visit)

9.2.5 Range of Fetal Anomalies

Table 16 reflects the range of fetal anomalies experienced by couples attending the clinic:

Fetal anomaly	Number	Fetal anomaly	Number
Chromosomal	15	Metabolic disorders	0
Renal	9	Cloacal plate	0
Cardiac	15	Fetal hydrops	2
Neural Tube defects	8	CAM	1
Gastro-intestinal defects	4	Lumbar/thoracic teratoma	0
Skeletal	2	CNS anomalies	7
Diaphragmatic hernia	5	Neonatal alloimmune	1
Cleft lip/palate	1	thrombocytopenia	1
Twins (Anomalies / TTTS)	3	Bilateral hydrothoraces	3
Caudal regression syndrome	0	Fetal akinesia	1
Laryngeal atresia	0		

Table 16. Previous fetal anomaly of patients attending PPCC

9.2.6 Range of maternal disease

Table 17 reflects the range of maternal disease experienced by women attending the clinic.

Maternal disease	Number	Maternal disease	Number
Hypertension	29	SLE/APS	21
Diabetes	5	Uterine anomaly	5
PCO	4	Cervical weakness	7
Thyroid disease	1	Cervical amputation	4
Renal disease	15	Arthritis	3
Chromosomal	5	Thrombophilia	11
Cardiac	2	Rhesus disease	7
DVT/PE	10	Epilepsy	3
Cholestasis	3	Stroke	2
Depression	2	Paraplegia	1
Fibroids	4	Infertility	8
Endometriosis	2	Crohns/Ileostomy	2
Group B strep.	2	Asthma	1
Osteogenesis imperfecta		Antiplatlet antibodies	2
Type 4	1	Sickle cell	1
Methadone user	1	Osteopetrosis	1
Myasthenia gravis	1		

Table 17. Maternal disease in patients attending PPCC

10 Conclusion.

This is a comprehensive report documenting a summary of the multidisciplinary work taking place in the Fetal Medicine Centre. It is hoped that this information will be of help to those working with the profession, the clinicians that refer us patients, the RSSG and the patients using the service.

Within these data are the entire core audits that underpin our clinical practice and provide a working model of clinical governance in action. It is a testament to all those who work with us to provide excellent clinical care.

Mark Kilby MB BS, MD, MRCOG
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Birmingham Women's Hospital, University of Birmingham, Metchley Park Rd, Edgbaston,
BIRMINGHAM, UK, B15 2TG.

Appendices

Staff list

Academic Staff

- Professor Mark D Kilby – Clinical Coordinator in Maternal and Fetal Medicine (NHS); Deputy Head of Division of Reproduction & Child Health (Academic).

NHS Staff

- Mr Peter Thompson – Consultant Obstetrician and Clinical Director
- Mr Bill Martin – Consultant in Fetal Medicine
- Dr Tracey Johnston – Consultant in Fetal Medicine
- Dr Gill Nava – Associate Specialist
- Dr John Wright – Lead Paediatric Cardiologist
- Dr Paul Miller – Consultant Paediatric Cardiologist
- Dr Ellen Knox – Subspecialty trainee in Fetal Medicine
- Dr Sam Pretlove - Subspecialty trainee in Fetal Medicine

Note: In 2008 Mr Gee stepped down as Medical Director, and Mr Thompson took up the post. The post of Clinical Director for Maternity Services was assigned to Dr Johnston. Roles above are correct for period of report.

Obstetric Radiology staff

- Dr Josephine McHugo – Consultant Obstetric Radiologist
- Lida Debono – Radiographer Advanced Practitioner
- Nicola Brealey – Radiographer Advanced Practitioner
- All obstetric radiographers at BWHCT

2.4 Nursing/Midwifery Staff

- Veronica Donovan – Matron
- Helen Baker – Specialist Midwife
- Nia Carnevale – Specialist Midwife
- Ruth Kirchmeier – Specialist Midwife
- Gill Jongman – Specialist Midwife
- Brenda Boldger – Specialist Midwife
- Maria Masood – Specialist Midwife
- Jane Meredith – Specialist Midwife
- Sarah Hall – Specialist Midwife
- Sandra Smith – Midwifery Assistant
- Frances Rich – Midwifery Assistant

Administrative Staff

- Becky Williams –Assistant General Manager: Maternity, Fetal Medicine & Neonates
- Samantha Mostyn – Administrator
- Emma Prentice – Clinic Secretary
- Elaine Jennings – Receptionist
- Alison Hill – PA and Secretary to Prof Kilby, Mr Thompson & Mr Martin
- Elaine Smith - PA and Secretary Mr Thompson, Mr Martin & Prof. Kilby.
- Vicki Morrison- Thomas – Pre-pregnancy Clinic Secretary

Consultants supporting the Pre-Pregnancy Counselling/Pregnancy Loss Clinic

Mr Bill Martin carries out a monthly Pre-pregnancy Counselling/Pregnancy Loss Clinic and is in addition one of the lead consultant obstetricians for the management of multiple pregnancy.
Mr Peter Thompson carries out a monthly Pre-pregnancy Counselling/Pregnancy Loss Clinic and in addition is the lead consultant obstetrician for the regional adult cardiology clinic.
Mrs Tracey Johnson carries out a monthly Pre-pregnancy Counselling/Pregnancy loss Clinic and in addition is the lead consultant obstetrician for the regional immunology, renal and diabetic clinic.
Professor Mark Kilby carries out a monthly combined Genetic/Pregnancy Loss Clinic.

The following Consultants are available for combined appointments with the Maternal Fetal Medicine Consultants:
Dr Louise Brueton (Consultant Geneticist) Dr Graham Lipkin (Consultant Renal Physician)
Dr Sarah Thorne (Consultant cardiologist) Dr Caroline Gordon (Consultant Rheumatologist)

PCT name	Total
BIRMINGHAM EAST AND NORTH PCT	277
COVENTRY TEACHING PCT	99
DUDLEY PCT	521
HEART OF BIRMINGHAM TEACHING PCT	671
HEREFORDSHIRE PCT	161
NORTH STAFFORDSHIRE PCT	60
SANDWELL PCT	658
SHROPSHIRE COUNTY PCT	31
SOLIHULL CARE TRUST	105
SOUTH BIRMINGHAM PCT	1295
SOUTH STAFFORDSHIRE PCT	526
STOKE ON TRENT PCT	125
TELFORD AND WREKIN PCT	47
WALSALL TEACHING PCT	382
WARWICKSHIRE PCT	487
WOLVERHAMPTON CITY PCT	74
WORCESTERSHIRE PCT	643
Subtotal WMSSA	6162
Subtotal OAT	575
Total	6737

Table 18 Fetal Medicine activity (examinations) by PCT 2008-2009
Source: Viewpoint

PCT name	Total
BIRMINGHAM EAST AND NORTH PCT	50
COVENTRY TEACHING PCT	2
DUDLEY PCT	83
HEART OF BIRMINGHAM TEACHING PCT	146
HEREFORDSHIRE PCT	2
NORTH STAFFORDSHIRE PCT	1
SANDWELL PCT	76
SHROPSHIRE COUNTY PCT	2
SOLIHULL CARE TRUST	18
SOUTH BIRMINGHAM PCT	284
SOUTH STAFFORDSHIRE PCT	36
STOKE ON TRENT PCT	1
TELFORD AND WREKIN PCT	1
WALSALL TEACHING PCT	26
WARWICKSHIRE PCT	17
WOLVERHAMPTON CITY PCT	8
WORCESTERSHIRE PCT	65
Sub Total WMSSA	818
Sub total OAT	8
Total	826

Table 19 PPCC activity (outpatient attendances) by PCT 2008-2009
Source: iPM