



NEWSLETTER 56 - January 2019

New study - Fontan and Pregnancy

Background: The Fontan repair describes a palliative surgical procedure that is undertaken for patients born with a congenital heart defect that cannot support a biventricular circulation. Congenital heart disease is the most common congenital abnormality, affecting one in one hundred babies, and the number of adults who have undergone a Fontan repair is increasing. Historically women were advised against pregnancy because it was felt to be too high risk, but in the last 10 years we have more retrospective data to show that these women are able to carry a pregnancy, albeit with a relatively high rate of complications.

Women with a Fontan circulation are known to have a higher rate of miscarriage (some studies report rates of almost 70%) and a higher rate of postpartum haemorrhage than any other congenital heart disease group. There is no consensus on whether women with a Fontan circulation should routinely be offered anticoagulation during pregnancy (either at prophylactic or therapeutic dosing levels). It is also unknown whether pregnancy accelerates the progressive deterioration of the function of a Fontan circulation.

The aims of this study are to prospectively collect data on a cohort of women embarking upon pregnancy with a Fontan repair to describe current pregnancy management and outcomes and to evaluate if pregnancy has a detrimental impact upon cardiac function in the short term.

Surveillance Period: 1st January 2019 – 31st December 2021

Case Definition: All women with prior Fontan repair who have a pregnancy, regardless of outcome.

Investigators: Matthew Cauldwell and Mark Johnson, Chelsea and Westminster; Michael Gatzoulis, Royal Brompton; Philip Steer, Imperial College: Marian Knight, NPEU.

Further details about the study (including the full protocol) are available at **www.npeu.ox.ac.uk/ukoss**.



Thank you!

A special thank you goes to Bill Martin who is retiring from Birmingham Women's Hospital and therefore retiring as a UKOSS reporter. Bill has been an extremely reliable reporter, always completing monthly reports and returning data collection forms promptly and will be missed by the UKOSS team. We wish him a very happy retirement!

Reminder – Seasonal Influenza and Low Maternal Plasma Fibrinogen

The Seasonal Influenza and Low Maternal Plasma Fibrinogen studies have now ended; therefore, please ensure that you return all outstanding data collection forms as soon as possible so that we can begin collating the data for analysis. We would particularly like to remind you to complete the Influenza CONTROL forms as there are still a large number that have not yet been returned to us. Please contact us at ukoss@npeu.ox.ac.uk if you would like us to confirm which forms (if any) are still outstanding for your unit.



- Interview with a UKOSS Reporter
 - Confirmed UKOSS studies starting this year



Thanks to the following hospitals who have returned reports for September, October and November 2018:

Aberdeen Maternity Hospital Altnagelvin Area Hospital Arrowe Park Hospital Ayrshire Maternity Unit

Barnsley Hospital NHS Foundation Trust

Basildon Hospital Bedford Hospital Birmingham Hear

Birmingham Heartlands Hospital Birmingham Women's Hospital Borders General Hospital Bradford Royal Infirmary Bronglais Hospital Broomfield Hospital Calderdale Royal Hospital

Causeway Hospital

Chesterfield & North Derbyshire Royal Hospital

City Hospitals Sunderland NHS Trust Colchester General Hospital Countess of Chester Hospital Cumberland Infirmary

Daisy Hill Hospital
Darent Valley Hospital
Darlington Memorial Hospital

Derby Hospitals NHS Foundation Trust

Derriford Hospital

Diana Princess of Wales Hospital Doncaster Royal Infirmary Dorset County Hospital

Dumfries & Galloway Royal Infirmary

East Surrey Hospital

East Sussex Healthcare NHS Trust

Epsom General Hospital Forth Valley Royal Hospital Frimley Park Hospital Furness General Hospital George Eliot Hospital

Glan Clwyd District General Hospital

Good Hope Hospital Harrogate District Hospital Hereford County Hospital Hinchingbrooke Hospital NHS Trust

Homerton University Hospital

Hull Royal Infirmary Ipswich Hospital

James Cook University Hospital
James Paget University Hospitals Trust

Jersey General Hospital Kettering General Hospital King's College Hospital King's Mill Hospital Kingston Hospital

Lancashire Teaching Hospitals

Lancashire Women and Newborn Centre

Leeds General Infirmary Leicester Royal Infirmary Lincoln County Hospital Lister Hospital

Luton & Dunstable Hospital

Macclesfield District General Hospital

Manor Hospital

Medway Maritime Hospital

Milton Keynes Hospital NHS Foundation Trust

Musgrove Park Hospital Nevill Hall Hospital New Cross Hospital Newham General Hospital

Nobles Hospital

Norfolk & Norwich University Hospital

North Devon District Hospital North Manchester General Hospital

Northampton General Hospital Northumbria Specialist Emergency Hospital

Nottingham City Hospital Peterborough City Hospital

Pilgrim Hospital

Pinderfields General Hospital Prince Charles Hospital Princess Alexandra Hospital Princess Anne Hospital Princess Elizabeth Hospital Princess of Wales Hospital Princess Royal Hospital Princess Royal Hospital

Princess Royal Maternity Hospital Princess Royal University Hospital

Queen Alexandra Hospital Queen Elizabeth Hospital Queen Elizabeth Hospital Queen Elizabeth Hospital

Queen Elizabeth the Queen Mother Hospital

Queen's Hospital
Queen's Medical Centre
Raigmore Hospital
Rosie Maternity Hospital
Royal Albert Edward Infirmary
Royal Alexandra Hospital
Royal Berkshire Hospital
Royal Bolton Hospital
Royal Cornwall Hospital
Royal Devon & Exeter Hospital

Royal Free London NHS Foundation Trust

Royal Glamorgan Hospital Royal Gwent Hospital

Royal Jubilee Maternity Service Royal Lancaster Infirmary Royal Oldham Hospital Royal Surrey County Hospital Royal Victoria Infirmary Russells Hall Hospital Salisbury District Hospital

Sandwell & West Birmingham NHS Trust

Scarborough Hospital
Scunthorpe General Hospital

Simpson Centre for Reproductive Health

Singleton Hospital

South Tyneside NHS Foundation Trust

South West Acute Hospital

Southend University Hospital NHS FT

Southern General Hospital

St Helier Hospital

St James's University Hospital

St John's Hospital St Mary's Hospital St Michael's Hospital St Peter's Hospital St Richard's Hospital Stoke Mandeville Hospital

The Great Western Hospitals NHS Foundation

Trust

The Portland Hospital Torbay Hospital Ulster Hospital

University Hospital Lewisham

University Hospital of Coventry & Warwickshire

University Hospital of North Durham University Hospital of North Midlands

University Hospital of North Tees

Victoria Hospital Victoria Hospital

Warrington and Halton Hospitals NHS FT

Warwick Hospital

West Cumberland Hospital West Middlesex University Hospital

West Suffolk Hospital
West Wales General Hospital
Western Isles Hospital
Wexham Park Hospital
Whiston Hospital
Whittington Hospital
William Harvey Hospital
Wishaw General Hospital
Worcestershire Royal Hospital

Worthing Hospital
Wrexham Maelor Hospital
Wythenshawe Hospital
Yeovil Women's Hospital

York Hospital

Ysbyty Gwynedd District General Hospital

Airedale General Hospital

Antrim Hospital

Bassetlaw District General Hospital Chelsea & Westminster Hospital Craigavon Area Hospital Croydon University Hospital Gloucestershire Royal Hospital Leicester General Hospital

Ninewells Hospital & Medical School North Middlesex University Hospital

Northwick Park Hospital

Poole Hospital

Queen Charlotte's and Chelsea Hospital Rotherham District General Hospital

Royal Free Hospital

Royal Sussex County Hospital

Southport & Ormskirk Hospital NHS Trust

St George's Hospital
St Mary's Hospital
St Mary's Hospital
Stepping Hill Hospital
Tameside General Hospital

The Hillingdon Hospitals NHS Foundation Trust

The Jessop Wing University College Hospital

Watford General Hospital

Whipps Cross University Trust Hospital

Guy's and St Thomas' Hospital

Leighton Hospital Royal London Hospital Southmead Hospital The Tunbridge Wells Hospital John Radcliffe Hospital Liverpool Women's Hospital North Hampshire Hospital

Queen's Hospital Royal Hampshire County Hospital

Royal United Hospital
University Hospital of Wales

Returned all three reports. Returned two reports. Returned one report. No reports returned.



BPSU Surveillance of invasive Listeria infections and neonatal herpes simplex disease

In September 2017, the British Paediatric Surveillance Unit (BPSU) began surveillance of listeria infection in infants less than 90 days. The study aims to establish the incidence of listeria infection in young infants, define whether some ethnic groups or geographical areas are more affected and describe the management and clinical outcome of the infected babies in the UK and Ireland. It is anticipated that the results will inform national antibiotic policy for young infants.

In addition, this year BPSU is also launching a new surveillance study to capture the incidence of neonatal herpes simplex disease in infants less than 90 days of age in the UK and Ireland as well as describe the presentation, management and outcomes.

For both these studies the BPSU has sought the assistance of UKOSS, although we anticipate the impact on UKOSS reporters will be minimal. Cases will be identified by paediatricians through BPSU and through collaborations with microbiologists and virologists. In some cases the maternal and birth details will not readily be available to paediatricians; it is therefore hoped that if approached by the paediatrician reporting the case, the UKOSS reporter will assist in obtaining the necessary information which the paediatrician will then use to complete the study proforma. Please note that UKOSS reporters will not be required to report cases or complete data collection forms.

The Listeria study is led by Dr Stefania Vergnano (Bristol Royal Hospital for Children) and Prof Paul Heath (SGUL). If you have any questions please contact Dr Stefania Vergnano at *stefania. vergnano@uhbristol.nhs.uk* and the HSV study is led by Dr Katy Fidler (Brighton and Sussex Medical School and Royal Alexandra Children's Hospital) and Prof Paul Heath (St George's University of London (SGUL)). If you have any questions please contact the study coordinator Dr Julia Dudley at *Julia.Dudley@bsuh.nhs.uk*.

Please contact UKOSS if you have any queries regarding the above.

New studies this year

Three new studies have been confirmed to start this year - Diabetic Ketoacidosis, Hyponatraemia in Pregnancy and Impacted Fetal Head at caesarean section. The study documentation for these is currently being finalised. More information will be circulated in due course but in the meantime if you have any queries then please do not hesitate to contact us at ukoss@npeu.ox.ac.uk.



Chocolate Box

Chocolates this month go to **Elizabeth Turner**, Norfolk and Norwich Hospital,
and **Paquita Sanges**, Royal Gwent
Hospital, for prompt return of reports
and data collection forms.

Many thanks to you both!

Case report summary for current studies up until the end of November 2018

Disorder	Actual number of reported cases	Data collection forms returned (%)	Expected number of confirmed cases
Amniotic Fluid Embolism	279	268 (96)	167
Cirrhosis in Pregnancy	47	39 (83)	80
High Neuraxial Block	79	61 (77)	133
Low Maternal Plasma Fibrinogen	155	120 (77)	180
Near Miss Suicide in Pregnancy	20	13 (65)	34
Seasonal Influenza	572	482 (84)	100

Read more online

To read this on your phone or to access our complete archive: Open the BARCODE READER APP* on your phone and scan the code here





Meet Sarah Davies who is a UKOSS reporter at Lancashire Women and Newborn Centre

Who is your employer and what is your job title?

East Lancashire NHS Trust – Consultant Obstetrician

Can you give a brief summary of your career to date?

I completed speciality training in the Northwest region in April 2018 and started work as a consultant obstetrician.

What are the main duties/responsibilities of your current role?

I currently have a joint diabetic antenatal clinic and a general antenatal clinic. I am the lead for the central birth suite for the trust. In this role I work alongside the obstetric risk team.

Please outline the difficulties that Lancashire Women and Newborn Centre have experienced in gathering information for UKOSS reports

Due to changes in personnel, there was period of time where UKOSS reporting within the trust temporarily ceased. Obtaining some of the cases retrospectively was very challenging, in particular flu cases in pregnancy. East Lancashire is a large trust based across two sites with the maternity and A&E services being situated separately. Admissions may be under a medical team with obstetric input at Blackburn or with the obstetric team based at Burnley. Confirmed flu cases are recorded but there is not record if the patients are pregnant at the time. There is no way of combining the current microbiology and maternity systems meaning it is likely some flu cases may have been missed in the period where reporting ceased. Other UKOSS reportable cases were easier to identify retrospectively through the risk management team and from individual clinicians.

Now that it is up and running again, how do you manage/co-ordinate the UKOSS reporting in your hospital?

There is better advertisement of the current UKOSS studies within the department with posters in all clinical areas.

We have a separate UKOSS email account which any staff member can use to report a confirmed or suspected case which can be followed up. This is particularly helpful in the case of suspected flu as all A&E attendances in pregnancy are logged and checked daily.

Each month an email is sent to all obstetric and anaesthetic consultants asking for any applicable cases.

Better communication with the quality and safety team and risk leads for both obstetrics and obstetric anaesthetics is now in place to improve detection.

There is now a link with the newly formed perinatal mental health clinic to improve detection rates of attempted suicide in pregnancy.

Have you found that there are additional benefits from reporting to UKOSS?

As a newly appointed consultant identifying and reporting cases to UKOSS has allowed me to develop a network with contacts across multiple specialities within the trust.

Would you recommend becoming a UKOSS reporter to others and if so, why?

Yes. The topics chosen are important, clinically relevant or rare. By collating information across the country useful recommendations can be used by all clinicians providing care. I have found it a useful educational resource for my ongoing personal development.

GMC Revalidation and NMC Continuing Professional Development



We are aware that as part of your GMC revalidation or NMC Continual Professional Development, you are required to provide evidence of participation in national audit and research. If any UKOSS reporters would like to receive a certificate confirming their contribution to UKOSS, please email us at ukoss@npeu.ox.ac.uk and we will get one posted out to you.



Admin team: 01865 289714

Email: UKOSS@npeu.ox.ac.uk **Web:** www.npeu.ox.ac.uk/UKOSS

