



## **Minutes of the SWCAR Steering Committee Meeting**

held on

Tuesday 1 July 2008

between 1.00 – 3.00 pm in

The Library, Clinical Genetics Department, Royal Devon & Exeter Hospital (Heavitree)

### **Present:**

Prof Peter Fleming (Chair), Infant Health & Developmental Physiology, SWCAR

Ms Julie Chamberlain, Information Administrator, SWCAR

Dr Emma Kivuva, Consultant Clinical Geneticist, Royal Devon & Exeter Hospital

Ms Beverley Lovering, Midwife Sonographer, Southmead Hospital

Mr Tim Overton, Consultant in Fetal Medicine, St Michael's Hospital

Ms Alison Phillips, Ultrasonographer Advanced Practitioner, Torbay Hospital

Ms Anne Schlegelmilch, Fetal Medicine Midwife, Southmead Hospital

Dr Sarah Smithson, Consultant in Clinical Genetics, St Michael's Hospital

Mr Ben Wreyford, Information Administrator, SWCAR

### **1.0 Apologies**

Apologies were received from Ms M Brooks, Ms J Ford, Ms A Knight, Dr J Madar, Dr R Martin and Mr S Savage.

### **2.0 Overview of SWCAR work**

For the benefit of the new members present, BW provided an overview of the work of the Register set up to provide an accurate source of data on congenital anomalies to aid surveillance of birth defects, by reporting to the Office for National Statistics, and to act as a resource for research, audit and service planning. The criteria for inclusion on the Register were outlined together with the importance of receiving notifications from a variety of sources, the need to ensure that mother and baby records were accurately linked together and the significance of precise diagnosis coding to allow for more powerful analysis. The processes available to SWCAR staff for follow up were also described.

The advantage of the SWCAR notification system was that collection of data was permanently open allowing for anomalies diagnosed as the child develops to be added retrospectively therefore updating and improving the quality of the data over time. SS mentioned that many syndromes were not diagnosed under the age of two and PF highlighted that the draft SWCAR 2006 data showed a significant number of cases diagnosed at one year plus and noted that it was very encouraging to see paediatricians were still interested in notifying the Register at this stage. PF reiterated that it was far better to over report than not to report at all.

EK asked if it was necessary to inform parents before notifying and PF explained no informed consent was required as the Register was covered under Section 60 of the Health and Social Care Act and had approval from the Patient Information Advisory Group (PIAG). Parents could, however, request their personal data be removed from the database leaving information about the anomaly remaining. In practice very few parents had asked for this to happen. SS was concerned that she should explain about the Register when leaflets were handed to parents but she was reassured that that was not necessary.

TO explained that it was important to be open about the Register in general and to remember that there were strict constraints on how the data could be used by researchers who needed to seek ethics committee approval. It was also good for some parents to know they were contributing to future research.

EK requested blank notification forms for her department to complete.

**Action: JC**

### **3.0 SWCAR website**

When the website was established it was agreed that as much information as possible should be included on the site. This had proved a huge asset for healthcare professionals across the south west region who can access their own hospital data and benefit directly from the notifications they have made.

An incident arose in October 2007 when a journalist published a completely inaccurate article for the Sunday Times "*Babies aborted for minor disabilities*" claiming more than 50 babies had been terminated for club feet in the south west region between 2002 and 2005. The data on the website had been misinterpreted to assume that these babies had been terminated solely because of talipes when, in all cases, talipes was just one of other more serious anomalies present. Although TO fully briefed the journalist several times about their error in advance of publication, the journalist chose to go ahead and print the article anyway. Shortly afterwards PF wrote to the Sunday Times to get this corrected but the letter was not published. Further correspondence was then sent to a number of MP's and supportive replies received. Although a statement had been included on the website to clarify how the data was presented, following this article an additional statement was added to reiterate this.

PF requested members take a look at the website, [www.swcar.org.uk](http://www.swcar.org.uk), and come back to him if they had any suggestions to make.

**Action: All members**

## **4.0 Use of SWCAR data**

### **4.1 Folic Acid Audit**

TO reported that Julie Mytton's paper *An evaluation of the recording of folic acid use in the South West Congenital Anomaly Register* had been accepted and was due for publication in *Prenatal Diagnosis*. This was an important piece of work which could promote further funding for registers, some of whom were finding it increasingly difficult to secure ongoing support as no central funding was available. It had been hoped that following the collaboration between the Department of Public Health and SWCAR more registrars would have been encouraged to get involved in research but that had not been the case to date.

### **4.2 FOCaL: (Follow-up Of Congenital Abnormalities Longterm),**

A body funded by the Birth Defects Foundation, the aim of FOCaL was to develop a standard methodology for the long term follow up of children with structural congenital anomalies or ultrasound soft markers and make this information widely available for counselling expectant parents.

All congenital anomalies registers were involved with the first study to look at all children born with congenital diaphragmatic hernia between January 2005 and June 2006 and investigate the status of these children at age two by contacting those paediatricians involved with their care. SWCAR was currently sending completed cases to the National Perinatal Epidemiology Unit for analysis, as and when the child reached age two.

This study had been extended for a further six months to include children with dates of birth up until the end of 2006. It was agreed to do this as a couple of registers had only recently gained R&D approval and the response to questionnaires sent out had been particularly poor.

### **4.3 Gastroschisis data**

TO reported that Helen Walters, one of his former students, had presented her paper looking at the incidence of gastroschisis in the south west region between 2002 and 2005 at the Perinatal Medicine 2008 conference in Harrogate. The data had shown that there had been a near doubling of the number of cases of gastroschisis in 2004 but it had since returned to more stable levels. Helen was currently writing up the work as a formal paper and it was hoped this would get published in due course.

The Fetal Medicine Unit at St Michael's was still involved in a multi-centre gastroschisis study where hair samples were being taken from woman and analyzed to identify lifestyle factors prior to and during pregnancy.

## **5.0 EUROCAT membership and implications**

PF explained that an application had been submitted towards the end of 2007 for the Register to become a member of EUROCAT (EU epidemiologic surveillance of congenital anomalies).

Initially membership proved difficult to obtain as the European register defines its members in terms of geographical area only but a problem arose as the Wessex Antenatally Detected Anomalies Register (WANDA), overlaps with part of the SWCAR region in Wiltshire. Negotiations with WANDA were ongoing to resolve this issue.

In the meantime EUROCAT have agreed that SWCAR could become an affiliated member at the outset which would be upgraded to full membership when high quality data could be provided for the whole geographical area.

## **6.0 Office for National Statistics (ONS) alerts from the National Congenital Anomaly System (NCAS)**

There was nothing to report.

## **7.0 Future SWCAR plans and priorities**

SWCAR was still receiving fixed ongoing funding via speciality commissioning from the PCT's but was in a better position than some other registers who were having difficulties receiving support year on year. The possibility of receiving central funding for all registers from the Chief Medical Officer was no longer an option after the issue was dropped suddenly last year without explanation. PF stated that the Register was more efficient than other registers as it was based in the same offices as the CEMACH and Child Death Review projects and received notifications via this route as well.

TO said he regularly attended obstetric meetings where discussion took place about the importance of receiving anomaly outcome data. He felt that the Register could be a useful source of this information and he suggested himself and PF draft a letter to Professor Peter Soothill in his capacity at the National Screening Committee requesting top level support for congenital anomaly registers.

**Action: PF/TO**

SWCAR hoped to improve links with the molecular genetics department at Southmead Hospital to pick up on metabolic disorders as they were diagnosed.

**Action: PF/TO**

PF was keen to encourage members to promote the Register to other trainees and for them to emphasise that although R&D approval was required it was not as difficult to obtain as might at first be thought. The data published since 2002 showed relatively stable number of anomalies year on year. SS asked if there were any specific projects that the Register had in mind and PF and TO felt that some examination of neural tubes defects/hydrocephalus data would be interesting, especially as a rising trend had been noted in the numbers of mothers who wished to continue with their pregnancy after diagnosis. It was also thought that a cardiac or clefting study would be valuable.

**Action: All members**

## **8.0 Any Other Business**

PF asked those attending the meeting if there was anything the Register could do to enable them to notify easier. AP felt the warning card system in place was useful but the difficulty came in remembering to fill in the form and then finding the time to do it. TO suggested, as Torbay was now using Viewpoint software, it was possible to set up an option to print an additional copy of the ultrasound report for SWCAR.

An alternative notification route offered to members was for discharge letters to be copied in to either PF or TO. To avoid confusion with letters about his own patients, TO asked if it could be made clear on the letter it was in his role with SWCAR. SS said she would send an email to her department to encourage reporting via PF.

**Action: SS**

Discussion took place about the frequency of future meetings and how to encourage members to attend, especially those from the peninsula. SS and EK suggested it may be easier to tag the steering committee meeting onto a future fetal medicine/paediatric gathering where members were more likely to be present.

EK reported that she would be on maternity leave from September until approx June 2009 but hoped to be able to set up a system of reporting before her departure.

**Action: EK**

## **9.0 Date of Next Meeting**

It was hoped the next meeting could be scheduled for December 2008. It was planned to circulate a selection of dates to members in advance and to settle on the location of the meeting depending on who was able to attend.

**Action: JC**