South West

Congenital Anomaly Register

Minutes of the SWCAR Steering Committee Meeting

held on
Thursday 11th October 2007
between 2.00 – 3.30 pm in
Tutorial Room 3, Level 4, UBHT Education Centre, Bristol.

Present:

Prof Peter Fleming (Chair), Infant Health & Developmental Physiology, Bristol University
Ms Julie Chamberlain, Information Administrator, SWCAR
Ms Cath King, Genetic Nurse Specialist, Royal United Hospital, Bath
Ms Julie Mytton, Specialist Registrar in Public Health, Bristol South & West PCT
Mr Tim Overton, Consultant in Fetal Medicine, St Michael's Hospital
Mrs Rosie Thompson, Project Manager, SWCAR
Dr Peter Turnpenny, Consultant Clinical Geneticist, Royal Devon & Exeter Hospital, Exeter

1.0 Apologies

Apologies were received from Ms M Brooks, Mr D Bryne, Ms J Drury, Ms J Ford, Mr S Grant, Ms A Knight, Dr R Martin, Ms J McNally, Mr L Osobo, Ms A Philips, Ms J Verne and Mr B Wreyford.

2.0 Overview of SWCAR work

Aileen McLoughlin, Co-ordinator, SWCAR, has resigned from the Register to pursue a career as an NHS Information Analyst and as a result RT explained this has left the Register with a staffing gap. No replacement would be made for this post at the present time due to funding issues. It was hoped that a new junior person may be employed on a part-time basis in the New Year to help existing staff with more routine tasks, but the main priority was to streamline existing working practices to maintain current levels of working approx 6 months in arrears. PF, TO, RT, JC and BW would be meeting on a monthly basis to review workloads and discuss any data requests and involvement in new projects.

TO was pleased to announce that Dr Sarah Smithson, Consultant in Clinical Genetics, would be joining the SWCAR Management Committee and would be able to offer a broad range of professional skills and that Dr Viv Harrison, Consultant in Public Health, was keen to get involved with the Register on an adhoc basis.

In response to inadequate notifications from Royal United Hospital, Bath, RT had visited the Child Health Department who would now provide copies of their congenital malformation forms to the Register each time they received one.

CK was concerned that postnatal clinical genetics follow-up forms sent out on a regular basis for verification to her would no longer be sent. JC reassured her that this system would continue even though Aileen had left the Register. **Action: JC**

PF asked about the possibility of any additional funding for the Register and RT explained that at the latest BINOCAR (British Isles Network of Congenital Anomaly Registers) meeting in September it was revealed that a negative response had been received from the Chief Medical Officer about a possible £1.1 million funding source which had previously appeared likely. RT also confirmed that an NHS review appeared to be taking place for funding of registers and other enquiries such as the Confidential Enquiry into Maternal and Child Health (CEMACH), although this was not being made public. PF revealed that two relevant public service agreements had been published linked to the Children's Act 2004 about keeping adequate records about children's medical conditions and safeguarding children, including the implementation of child death reviews, both of which would link in well with congenital anomaly registers.

3.0 SWCAR website

RT explained that data had been published on the website to the end of 2005 but following the resignation of Aileen McLoughlin work had not yet started on the production of data for 2006. PF suggested it should be a priority to get 2006 data on the website by the end of the year and RT explained that she planned to work towards that within the resources she had available.

Action: RT

RT hoped that in the future data available on the website could be manipulated by those individuals logging on and so lessen the workload for smaller data requests that the register received.

Action: RT

4.0 Use of SWCAR data

4.1 Folic Acid Audit

JM updated the meeting on her article *Use and recording of folic acid to prevent neural tube defects in pregnancy: South West Region, 2003-2004*. The audit's aims were to examine the completeness and accuracy of the recording of folic acid use (pre-pregnancy and during early pregnancy) in recent registered cases of neural tube defects in the south west region.

The article was submitted to the *British Journal of Obstetrics and Gynaecology* but was not published so it was decided to submit it instead to *Prenatal Diagnosis*, who had shown an interest in other papers from congenital anomaly registers. JM had spent some time negotiating to resubmit the article after a shortened deadline came into effect without warning but she had now been granted permission to resubmit which would happen shortly. TO congratulated her on her determination to get the article published. JM remarked the difficulties had occurred about how to "package" the article but that it would be prove useful to those who read it.

Action: JM

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 first project is a feasibility study only and if this process proves successful data collected will be analysed with a view to future publication.

4.3 Gastroschisis data

TO mentioned that one of his students, Helen Walters, had undertaken a project with Aileen McLoughlin looking at the incidence of gastroschisis in the south west region between 2002 and 2005. There had previously been a steady number of cases each year, approx 13-15, except for 2004 when there had been an increase to 30 cases. Other registers had not noticed a significant rise in cases for that year. Analysis of environmental factors, eg, heatwave in 2003/postcode analysis would take place. It was hoped that this data would be published and reported to all registers.

JC tabled a map of Plymouth pinpointing 7 postcodes of mothers whose babies had been diagnosed with gastroschisis in the Plymouth area so far in 2007. PF felt this was of interest but not significantly so as Plymouth had consistently shown higher numbers of cases over the years, possibly due to higher levels of social deprivation and drug use.

PF pointed out cases of gastroschisis had been rare prior to the 1970's and had been on the increase since 1988 when the higher levels had been sustained. TO highlighted that the study had noted associated anomalies with gastroschisis including talipes, anencephaly, hydronephrosis, clefting and eye anomalies, in a total of 9 cases out of the 72 cases identified. Previously it was recognised that gastroschisis was an isolated anomaly.

TO confirmed SWCAR had been approached by Hannah Broughton, Research Officer, on behalf of the Gastroschisis Aetiological Study Steering Group, Cardiff University, to take part in a case control study to investigate the aetiology of gastroschisis, investigating the effects of lifestyle, dietary and environmental exposures. TO and RT confirmed that consent would be given for involvement with this project as this would only mean a small amount of work for the Register initially identifying cases. The Study Group would then approach those woman who had been diagnosed with gastroschisis at the 18-20 week anomaly scan and invite them to take part in the study.

Action: TO & RT

5.0 Study into common polymorphisms and environmental factors

PF asked an open question to the Committee about how members felt about the possibility of the future collection of cases of polymorphisms. He explained that polymorphisms were not routinely collected at the moment and acknowledged that it raised a debate about the ethical issues of keeping information on a baby's DNA. PT wondered who would supply the notifications as genetic testing was not done on a routine basis. He also pointed out that most parents who had been offered the opportunity to store DNA had done so readily. PF explained cultures were now routinely frozen in cases of sudden unexpected deaths to help identify causes in the future.

After much discussion, there was a general consensus amongst members that the Register could be used to record whether a sample of DNA has been taken and stored and that this could speed up future research by identifying cases in advance with stored DNA.

6.0 Application for EUROCAT membership

RT explained that SWCAR had decided to make a formal application to join EUROCAT (EU epidemiologic surveillance of congenital anomalies). The basis of this organisation was to provide essential epidemiologic information on congenital anomalies in Europe. This application for membership would be discussed at the next EUROCAT Project Management Committee meeting on 26-27 November. If accepted, RT stressed that it should not create much of an additional workload nor be expensive from an IT perspective as EUROCAT could provide software programmes to upload the data.

7.0 Office for National Statistics (ONS) alerts from the National Congenital Anomaly System (NCAS)

ONS regularly send out alerts about concerns over increased cases of anomalies over certain time periods, a copy of which is also sent to the Director of Public Health. Previously these alerts, as RT explained, were not acted upon by the Strategic Health Authority as it was known the Register was receiving increased numbers of notifications year on year. Recently more significant alerts had been received from ONS for cardiac and renal anomalies. However, Aileen McLoughlin had rechecked data from ONS against Register data and could not find any evidence of the increases in anomalies that ONS were concerned about.

Aileen felt this may have been due to a backlog of 2003-2005 data which was notified to ONS some time after this period and were not detected by the ONS surveillance software, hence the appearance of a recent increase in anomalies. Also reporting of these particular anomalies to the Register had recently improved with better systems for follow up and confirmation. Following feedback from the Register, ONS then discovered that their alert levels had been set too low for the period concerned thus generating unnecessary warnings. ONS are due to re-run these alerts shortly.

PF highlighted that each time an alert arrived it was important that the data was reanalysed and the Strategic Health Authority and ONS informed if any discrepancies were noted. RT would make contact with Julia Verne, Consultant in Public Health, South West Public Health Observatory about this matter. **Action: RT**

8.0 Future SWCAR plans and priorities

RT emphasized that the future plan was to run the Register as efficiently as possible and get all reporting up to date.

PF stressed it was important that those who provided data to the Register were able to access the data on request and that the Register's main objective should be to facilitate and encourage that process. It's original long term aim was also to aid with the provision of future services.

PT enquired about the possibility of the Register getting more work published and RT explained that at the moment the emphasis was on getting the folic acid article published. TO explained that he hoped that when Dr Viv Harrison came on board this would give the Register more credibility. It was also felt that there was a need to motivate more registrars to be involved with the process and that ideally it would be beneficial to have one public health trainee per year allocated to the Register.

Both PF and TO felt the Register should continue to concentrate on focused projects whilst contributing to other wider studies.

9.0 Any Other Business

PT reluctantly informed the committee that due to increasing work commitments he wished to step down from the Steering Committee. He suggested that Dr Emma Kivuva, Consultant Geneticist, Royal Devon & Exeter Hospital would be an ideal, enthusiastic replacement for him. He thanked the Committee for the interesting work he had been involved in over the last few years. PF thanked him very much for his advice and assistance throughout his membership and RT reiterated that she had greatly valued his support during the initial set up of the Register.

10.0 Date of Next Meeting

The date of the next meeting was still to be arranged.