



Scottish Genital Anomalies Network

NEWSLETTER
SUMMER 2009

Aims of the Newsletter

- Provide an update on SGAN audit activities
- Disseminate relevant news and research in the field of disorders of sex development
- Promote links between professionals and support groups involved in managing genital anomalies.

New Developments

- The information leaflet on Undescended Testes (Cryptorchidism) is in the draft stage. This will be available for distribution by the end of 2009.
- The new SGAN registration form is being used more widely now to register patients. This form and guidelines for completing are available on the SGAN website.
- The Network is committed to involving parents/carers/patients and is hoping to organise awareness sessions. A leaflet has been developed to send out to parents/carers/patients asking for their views on getting involved. Please contact the Network office for more information.
- **SGAN Annual Report** is available online at the website or from the MCN Office.

VOICES Scotland

The MCN department are running Voices Scotland training in conjunction with Chest, Heart and Stroke Scotland. The Voices Scotland project aims to provide patients/parents/carers with the skills and confidence to work with health professionals to influence change.

This is part of the SGAN network's plan to build parent/carer Forums across Scotland. If you know of a parent/carer who may be interested in getting involved with the network, please contact Maureen Kinney in the SGAN office.

CHI numbers and delayed sex of rearing

Prof Ahmed has come across at least two cases where the clinicians were having difficulty initiating investigations and creating medical records as they did not want to immediately commit the newborn child to a male or female sex. The CHI system at present defaults to male as the number construct includes a gender indicator. A new CHI system is in the development stage and will incorporate a number that is not tied to gender which will deal with the issue raised here and also the gender reassignment cases that currently cause similar issues. Advice from ISD at present is if gender is indeterminate and a number is needed then go with current system and if it's a girl then a new number will be needed.

Current Literature

Cryptorchidism and Testicular Cancer: Separating Fact From Fiction.

The Journal of Urology, Volume 181, Issue 2, February 2009, Pages 452-461.

Genomic imbalances in neonates with birth defects: high detection rates by using chromosomal microarray analysis.

Lu XY, et al
Pediatrics. 2008 Dec;122(6):1310-8

The descriptive epidemiology of congenital and acquired cryptorchidism in a UK infant cohort

Carlo L Acerini
Archives of Disease in Childhood: 18 Jun 2009:

New Study: Variations in the Development of the Female Reproductive Tract

Dr Ruth McGowan, SpR in Medical Genetics at Yorkhill is about to embark on a study that will evaluate the clinical features in women with a variation in the development of the reproductive tract, paying particular emphasis to associated anomalies in systems such as the kidneys and skeleton. This study will be coupled with hormonal and genetic studies that improve our understanding and classification of these conditions.

Women over the age of 16 years will be identified through the SGAN register and from specialists in surrounding hospitals. Through their local specialists, they will be invited to take part in the study and, where possible, they will be invited to attend Yorkhill so that the tests are carried out uniformly. In some cases, it may be more convenient for investigations to be performed locally and provision will be made for this.

It is expected that ethics approval will be granted in September with a view to starting recruitment that month. This is a multicentre study with collaborators in Aberdeen (Dr Susie Logan), Edinburgh (Dr Wayne Lam) and Glasgow (Dr Miriam Deeney, Dr Faisal Ahmed). Please contact Dr Ruth McGowan (Chief Investigator) for further details (ruth.mcgowan@ggc.scot.nhs.uk).

Forthcoming Events

ESPE DSD Group meeting 9 September 2009, New York
ESPU - Genitalia reconstruction workshop in conjunction with the VII annual ESPU Educational Committee course 2-3 October 2009, Madrid
3rd ISHID Congress (International Society on Hypospadias and Intersex Disorders DSD) 12-15 November 2009 Toronto

SGAN Annual Symposium 2010

The date for the next Annual Symposium is **Friday, 12 March 2010** please note in your diary.

2009 SGAN Clinics

These multidisciplinary clinics run every 3-6 months and SGAN members should contact the local clinic coordinators, if they wish to attend or if they want to refer any patient.

Visiting clinicians are welcome at any of the clinics at any of the sites. Please feel free to bring along your trainees to ensure they appreciate the spectrum of care and the advantages of a collaborative approach to patient care.

Dates of the next clinics

- **Aberdeen:** 3 December
- **Glasgow:** 5 October
- **Edinburgh:** 26 November

Dr A Mayo
Dr SF Ahmed
Dr P Midgley

SGAN Lunchtime Educational Meeting

This meeting is held between the SGAN Executive Group meeting and the Glasgow SGAN Clinic. If you would like to present at this meeting please contact Prof Faisal Ahmed. at RHSC. Glasgow (s.f.ahmed@clinmed.ola.ac.uk)

SGAN Fund – The SGAN fund is available to support trainees from any of the SGAN disciplines to attend meetings where they can present research or audit work based on the SGAN Register. Further details from Dr Faisal Ahmed.

STOP PRESS: Dr Faisal Ahmed has been awarded a personal chair at Glasgow, therefore his title is now Professor Ahmed. Congratulations Faisal from all in the network.

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Large print version of the newsletter is available from the SGAN Office