



PEGASUS

Professional Education
for Genetic Assessment and Screening

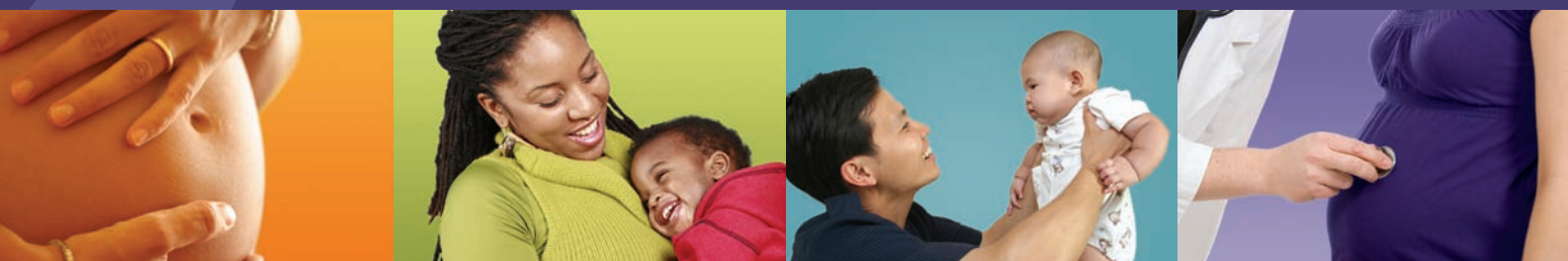
PEGASUS

Professional Education for Genetic Assessment and Screening

Delivering outstanding health professional training and education

PEGASUS has been successfully developing and providing training and education resources for health professionals involved in antenatal and newborn screening since 2005. It was funded by the NHS Sickle Cell & Thalassaemia Screening Programme which aims to improve infant health and help people make informed choices before conception and during pregnancy.

The PEGASUS programme has involved the collaboration of four NHS and academic institutions* led by Professor Joe Kai, Chair in Primary Care at the University of Nottingham. The critical importance of this work is indicated by the fact that haemoglobin disorders – sickle cell disease and thalassaemias – are the most common recessively inherited disorders in the UK.



Educational support has now been developed for:

Front line professionals, such as midwives, health visitors and GP's who routinely see patients;

Specialist counselling practitioners, who counsel women and couples at risk of having a child with an inherited disorder, and;

Public health professionals, who typically have public health and commissioning functions.

The learning format is designed to meet the needs of these groups who are further supported by freely available genetics information for practical use on the PEGASUS website.

www.pegasus.nhs.uk

* The University of Nottingham Division of Primary Care: National Genetics Education and Development Centre; Camden and Islington Sickle Cell and Thalassaemia Counselling Centre; Centre for Health Informatics and Multiprofessional Education (CHIME) at University College London

Over 600 NHS trainers created

A significant achievement of PEGASUS is the creation of over 600 NHS trainers who are committed local health professionals prepared to take on this role. This has meant that 95% of Maternity Trusts and over 60% of PCT's in England, along with some Universities and Voluntary Organisations have now benefited from a local PEGASUS trainer who has cascaded their knowledge through to front line professionals across England.

PEGASUS provides support to trainers in the form of regular regional support workshops and access to a password protected area on the website where they can download the latest training resources.

“

Comprehensive package; nothing of this quality around for haemoglobinopathies in the NHS. Well needed, well done!

”



Workplace training for front line professionals

Implementing a national training programme in the NHS is a significant challenge – one that has often defeated similar programmes. Therefore, it is a remarkable achievement to have facilitated training in real work settings for health professionals ‘in the front line’.

Interactive workshops led by PEGASUS Trainers

Front line health professionals have participated in discussion and debate around real life clinical scenarios. Those who attended training sessions have learnt about basic genetics, inheritance patterns (using sickle cell & thalassaemia as a model), diversity, enhancing practice and where to find more information for their patients.

“

I found the course a source of inspiration building on my knowledge of haemoglobinopathies. I really enjoyed it and I am now a valuable resource to my hospital on this subject.

”



These workshops have taken place across the NHS in England to large numbers of health professionals including midwives, GPs, health visitors, practice nurses and obstetricians.

Residential training for specialist counselling practitioners

The establishment of 5 day residential courses for specialist practitioners who counsel those at risk of having a child with an inherited disorder has been one of the most notable accomplishments of PEGASUS.

Over 200 specialists from many disciplines have been trained – including haemoglobinopathy counsellors, genetic nurses and antenatal screening coordinators. They participate in interactive group discussion, seminars and workshops lead by expert speakers and facilitators, with added benefit of sharing experiences and ideas with peers in an environment free of distractions.

Delegates are awarded the PEGASUS Approved Specialists' (PAS) award, enabling them to practice nationally as counsellors and Front Line Professional Trainers. This comprehensive course provides a baseline benchmark for training, now part of the NHS Sickle Cell and Thalassaemia Screening Programme Standards. This has never been achieved before in the NHS with this group of health professionals.

“I came on this course feeling pretty inadequate in my knowledge and having little confidence in communicating with couples and other professionals on the subject. I am leaving feeling excited, enthusiastic, confident and empowered – taking what I have learnt back to the heart of clinical practice.”



Online resources

PEGASUS has worked with some of the most popular online clinical systems, such as GP Notebook and EMIS Mentor, to make resources available for the busy clinician. Health professionals who receive laboratory screening results will have access to essential linked information and guidance from a pilot website currently being trialled. The ultimate aim is to implement a national system through which clinicians will be able to access this information via their IT clinical systems.



Online toolkit for public health and policymakers

This toolkit, designed to help estimate the likely investment, capacity and training requirements for haemoglobin disorder screening across a PCT, is the first resource of its kind for those professionals in busy public health or commissioning roles. It provides practical guidance for supporting local NHS initiatives and contains the necessary charts and tables to enable the assessment of the overall levels of need of a defined population to be expected at key stages in the screening pathway.

“

The guidance on how to be better at diversity issues is probably the best I have seen for health care practice.

”



Dedicated PEGASUS website www.pegasus.nhs.uk

The PEGASUS website has achieved widespread acclaim from healthcare professionals for its contribution to learning and practice. It is a 'live' source of learning support for each group of health professionals and an important facility for PEGASUS Trainers. It is a central repository for all PEGASUS training packages, bringing together knowledge and information in an easy to access and user friendly format.

“

I would like to congratulate you on your excellent PEGASUS website. It is really easy to navigate, and I have found it extremely helpful.

This is the first site like this that I've seen to provide information like this for practice.

”

www.pegasus.nhs.uk



PEGASUS - into the future

PEGASUS will continue to respond to the ongoing implementation of antenatal and newborn screening for haemoglobin and other genetic disorders in England, providing comprehensive training, education and support to health professionals. More importantly, with greater awareness of screening within the NHS, PEGASUS is going to be increasingly called upon to facilitate knowledge and support over the next 3-4 years.



www.pegasus.nhs.uk

Contacts

To learn more about PEGASUS please contact:

Tracey George
PEGASUS Programme Manager
tracey.george@nottingham.ac.uk
01332 724699

Joe Kai
Professor of Primary Care
joe.kai@nottingham.ac.uk

© July 2008 PEGASUS



*Antenatal and Newborn
Screening Programmes*