

An update on BADGEM

The clinical network for genetic skin disease

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BADGEM is a new initiative that has developed out of the recognised excellence in research in genetic skin disease in the UK. This has contributed to understanding the molecular basis of many monogenic skin diseases such as Epidermolysis Bullosa, and complex diseases such as eczema with the finding of filaggrin mutations in autosomal dominant ichthyosis vulgaris and atopic eczema. This work is expanding from applications in diagnosis into an exciting new era developing specific treatments targeted at the genetic defects. A group of scientists and clinicians, based mainly in Dundee, were awarded a strategic grant from the Wellcome Trust for: "Dermatology and Genetic Medicine" (DGEM), focused on drug discovery for new treatments and using next generation sequencing for genetic diagnosis. An important goal of this proposal was to set up a national clinical network so every patient with a geno-dermatosis (and their dermatologist) would have access to modern diagnostic techniques and know what treatments are being tested for their skin problem.

There are a number of very successful research networks and registers developed in collaboration with the BAD, in particular BADBIR and the new Translational Research Network for Dermatology (TREND) led by Nick Reynolds. It was suggested therefore that the clinical network for genetic skin disease should follow the same model in collaboration with the BAD. Happily, this suggestion was enthusiastically supported by the officers of the BAD and so BADGEM was born.

There are three work-streams currently active within BADGEM. One of the first needs is to develop a simple national register to record all patients. This will interface with the National disease register for rare diseases being developed in the UK and also the Genodermatoses European Rare Diseases Network. Neil Rajan is leading a working group to develop an electronic platform that will be hosted on the BADGEM web site, and we hope to launch this at the summer meeting of the BAD. A clinical and diagnostic signposting group is mapping the resources available for geno-dermatoses across the UK

and is led by Edel O'Toole and David Kelsell. A clinical trials group led by John McGrath and Adrian Heagarty is collecting information on ongoing clinical trials and coordinating advice for those starting new clinical trials. These trials do not use conventional drugs but include cell and gene therapy, which have lots of red tape to cut through before patients can be treated so it is important to share expertise. We were also invited by the British Society for Genetic Medicine to form a dermato-genetics group within their society and hold sessions at their annual meetings for geneticists to disseminate the wonderful research going on in the field of genetics in dermatology. John McGrath wowed their annual meeting talking about new treatments for EB.

BADGEM committed to running a clinical session at the annual meeting of the BAD and in Glasgow last year an excellent inaugural meeting resulted with wonderful speakers and case presentations. We are also planning a training programme in basic and applied genetics for clinicians to be started in 2016. A summer school in research techniques will also be held in Dundee as part of a Global Consortium in skin research including Japan (Keio), Koln, Denver, New York, Singapore and Dundee. We have planned another wonderful clinical meeting at the BAD annual meeting in Manchester on Thursday 9th July from 8.30-12.00. Maurice van Steensel, who has just moved to Dundee from the Netherlands as Professor of Dermatology to become clinical director of DGEM in future, will talk about using rare disease genetics to understand common diseases. Eli Sprecher will come again to the BAD to talk about rare genetic syndromes. Jem Rasbass, National (UK) Director of Disease Registration (cancer and rare diseases) will be telling us how our initiatives can interact with UK initiatives. Alan Irvine will update us on the latest news about filaggrin. We are awaiting confirmation from an eminent US speaker. There will also be many case presentations in both oral and poster format. So it will be another wonderful meeting and we hope to have standing room only again, so please put it in your diary and come and see what BADGEM can do to help your patients with geno-dermatoses. We hope to see you there.



The BADGEM Clinical Meeting at the BAD annual meeting in Glasgow in July 2014 was well attended