



# PIN

PRIMARY IMMUNODEFICIENCY NETWORK

NEWSLETTER VOLUME 4 ISSUE 1 AUTUMN 2003

## MANAGING THE FUTURE OF UK-PIN

**U**K-PIN is setting up a new on-line national register providing a minimum data set for the UK as part of its key aims for the next two years.

The register will be based on a reactivated UK steering group and will be run in conjunction with the ESID register. It is one of six priorities for UK-PIN, agreed by the steering committee this summer.

The group also wants to encourage participation in the ESID disease specific, outcome databases so that beneficial clinical information can be provided for the management of individual groups of patients with PIDs.

It is keen, also, to build on the progress it has made on accreditation. UK-PIN plans to continue discussions with UKAS to set up a process

enabling the organisation to become an accrediting body.

As part of this plan, all centres will be encouraged to work with local specialist commissioners on appropriate funding towards establishing accreditation awareness.

The Consensus document on diagnosing and managing Primary Antibody Deficiencies will be revised, providing evidence and involving trainees.

Finally, the organisation has agreed to firmly establish its own governance, to define the remit of its officers, periods of office, process for succession, responsibilities towards the membership and links with bodies such as the Royal Colleges, ACP, BSI and so on, to ensure UK-PIN is sustainable.

## OPEN DAY REASSURES ON 'RISKS' OF PEER REVIEW

**I**nnovative solutions could be generated by smaller Primary Immunodeficiency Centres that find it difficult to meet accreditation standards relating to cover, by developing network links with other centres.

Solutions for smaller centres were discussed during a UK-PIN organised open day at the Charities Centre in London to examine the practical issues of implementing standards for PID Centres. Concerns raised included worries from smaller centres who feared service cuts from Trust management if they fell short of inspection standards. Cover is a particularly difficult issue for small centres.

Overall feedback from the meeting was encouraging and centres that had been inspected were able to give feedback about the process and the benefits for them. Data was presented on the overall compliances from the centres visited. Dr Helen Chapel compared this with data collected from the self assessment exercise completed before inspections began.

Pilot sites have done much work on inspection, along with the guidelines working group, and all are happy to share documentation with centres preparing for review.

UK-PIN intends to maintain the informal peer-review approach to assessment against standards, until the organisation has achieved the standard re-

quired by UKAS as an accrediting body. It will be working slowly towards accreditation, since it will be time consuming and costly.

The latest version of the standards (v6) is available for downloading from the website. It incorporates learning points from pilot site visits.

Patients' views of the service must be obtained as part of the visit. UK-PIN plans to collect these on a standard form. Teresa Green and Fran Ashworth are co-ordinating the development of a form, with the PiA.

### WEB NEWS

UK-PIN is grateful to Carrock Sewell for his work developing the website and is now employing a web-manager to maintain it. The web address is [www.pinguidelines.org.uk](http://www.pinguidelines.org.uk)

We are obtaining the domain address [UKPIN.org.uk](http://UKPIN.org.uk) and will link the guidelines and main sites.

Feedback about the site is valuable, so please let us know what you think. Is there anything else you would like on the site? If you have important notices such as meetings, research collaborations, job adverts, forward them to Olga in the Office and she will ensure they go onto the website.

By the time you read this, UK-PIN will have hosted a successful meeting in York and celebrated its fourth year of existence. You will have seen from emails circulated by the office that the Chairman, Treasurer and Secretary plan to step down over the next year. We are still seeking nominations - any member of the UK-PIN Group is eligible to stand. In this newsletter, we have incorporated the report from Helen Chapel on behalf of the Steering Committee, on how much has been achieved over the last four years and what remains to be done.

The website has been developed further (see p.1) but we need people to use the it. In particular, we need more people to look at the guidelines and provide feedback to the writing group who have worked hard on this. Even comments such 'yes, I agree' would boost their morale!

The pilot phase of accreditation is complete and has been written up for publication. Overall the visits have been well received and have released new resources to centres. We are keen to get out to other sites and have organised a training day for potential centres which has dispelled a lot of myths.

We are still short of applications for the nurse and consultant exchanges: this is extremely disappointing as there is funding going begging. The PiA has agreed to support this initiative and I am sure that increasing staff exchange will benefit patient care – so get onto the office and lets have some applications.

Next year is ESID in Paris, so now is the time to be thinking about posters. The Chairman has been involved, with the PiA, in promoting research in PIDs to the Wellcome Trust, who are supportive of the importance of funding research in small disciplines. No ring-fenced cash I am afraid.

**Gavin Spickett**  
Editor

## YOUR VIEWS ON THE CONSTITUTION

A draft constitution has been uploaded onto the website. Please give us your views. For the time being, we plan no significant changes to UK-PIN. We do not plan to turn this into a formal organisation, or require paid membership. The activities remain supported for the time being by a core educational grant from BPL. We do seek to involve the immunology community in the organisation and running of the organisation.

Steering Committee members are:

**Helen Chapel** [completes term of office January 2004]  
**Gavin Spickett** [completes term of office June 2004]  
**Tim Wallington** [completes term of office December 2004]  
**David Webster**  
**Matthew Helbert** [responsible for Guidelines Writing Group]  
**Carrock Sewell** [responsible for Website]  
**Graeme Davis** [responsible for Register]  
**Alison Jones** [industry liaison]  
**Amolak Bansal** [consensus]  
**Teresa Green**  
**Fran Ashworth**  
**Richard Herriott** [ex-officio, Chairman of ACP Immunology Committee]  
**Andrew Cant** [ex-officio, Chairman of PiA Medical Advisory Panel]

Other members of the Steering Committee will be stepping down in rotation. We are concerned to ensure that there is a degree of continuity. During the last year, Nicky Brennan has resigned from the Committee, as she has retired from clinical practice. We have been very grateful to Nicky for her input and support in the early days of UK-PIN.

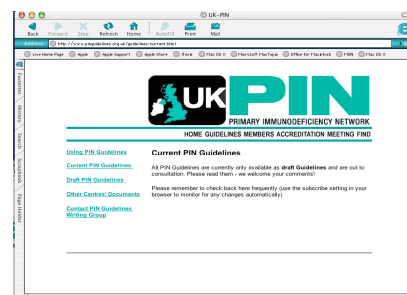
## MORE GUIDELINES POSTED

The writing group has been busy and there are now 12 guidelines posted. However, comments on the content are needed. Go and look at them on the website.

They are:

- 1.02 Writing PIN Guidelines
- 2.01 Administration of IVIG
- 3.01 Administration of SCIG
- 4.01 Consent to immunoglobulin therapy
- 5.01 Monitoring PID patients on immunoglobulin
- 6.01 Diagnosis and management of transient hypogammaglobulinaemia of infancy
- 11.01 SCID Initial diagnosis and management
- 12.01 Di George Syndrome diagnosis and management
- 13.01 XHIM diagnosis
- 14.01 XHIM management
- 15.01 Home IVIG therapy
- 16.01 Antibiotics at home

The writing group would also welcome suggestions for other topics which need new national guidelines.



To view the guidelines on-line visit  
[www.pinguidelines.org.uk/guidelines-current.html](http://www.pinguidelines.org.uk/guidelines-current.html)

# THE STORY SO FAR: REPORT ON UK-PIN 2000-2003

## AIMS AND ORGANISATION

UK-PIN is a multidisciplinary organisation devoted to those primary immunodeficiencies included within the specialist definition of Clinical Immunology – definition 16 (approved by the Department of Health). The network was set up to improve PID patients' care by developing common approaches to management through agreed standards of care. Help is provided through model protocols (policies, procedures and guidelines), based on common practice. These are available on the website for downloading by individual centres who wish to use them as the basis of local protocols.

So that treatment centres can demonstrate good practice, a scheme for accreditation has been introduced. This is a way of measuring compliance with the care standards. Following wide spread discussions and consensus on the nature of the standards, a self-assessment exercise was done. Pilot visits have been undertaken as part of the peer-reviewing assessment process. Details of these will be on the website soon.

UK-PIN has also provided a focus for consultation with regulators, manufacturers and NHS commissioners. It seeks to provide a means to influence decision-making processes within the UK and Europe, through representation on behalf of doctors and nurses and scientists working in the field of PID. It is also important to improve knowledge of PIDs through supporting research and encouraging clinical trials of new treatments and therefore has close liaison with the PiA, which represents patients.

All nurses, scientists and medical practitioners involved in the health-care of patients with primary immune deficiencies, or in research into these diseases, are deemed to be members of UK-PIN. A list of members is held at the UK-PIN office, which is established in the Department of Immunology, Royal Victoria Infirmary, Newcastle upon Tyne, with a part time clerical officer. A voluntary steering committee has been established; officers include the chairman, secretary, industry liaison officer and treasurer. Other committee members are co-opted to ensure balanced representation. Groups / working parties have been established as required, to deal with specific issues such as a new UK register, protocol writing, accreditation.

Currently, UK-PIN is entirely a volunteer organisation, ratified by the open biennial Immunology Forum. It is formally approved by and affiliated to the Council of the Association of Clinical Pathologists. The Chairman of the ACP Immunology Committee is an ex officio member of the UK-PIN steering committee.

Funding has been generously provided by an annual block grant from BPL. This covers administrative expenses. Additional income could be generated from educational activities. UK-PIN provides a Newsletter to members at least twice a year (also funded by an educational grant from BPL) and a web-site for posting draft documents (such as revised standards and protocols) for consultation as well as items of information.

## WHAT WE'VE ACHIEVED

### ★ DEVELOPED COMMON APPROACHES TO MANAGEMENT

Standards developed to enhance diagnosis, care and management of patients with PIDs were agreed by the profession at an open meeting

in October 2000. The process was validated by an initial self-assessment exercise in which 17 centres took part, showing compliance was achievable and appropriate.

### ★ PEER REVIEW ACCREDITATION SCHEME

Voluntary applicant centres have submitted details of their services and 2 consultants and a senior nurse have visited over 2 days to assess compliance with the standards. Five pilot visits have been made and the outcome of those visits and the modifications needed for the final accreditation process submitted for publication. The scheme has been modified in the light of experience and details will be posted on the website. If approved by members at the biennial meeting in November 2003, the scheme will go live in 2004. Considerable emphasis has been put on the opportunity for nurses and clinicians to share ideas and to collect and consider the views of patients.

### ★ TRAINING FOR ACCREDITATION

UK-PIN Assessors, including consultants with previous training in accreditation procedures by Clinical Pathology Accreditation [CPA] and senior nurses, have been trained in assessment and standards. There are now 10 nursing and 11 medical fully-trained assessors; further training days for new assessors are being held annually. An open information/training day was held in September for all potential applicants in order to make the process clear and to discuss any concerns. Further days will be held next year.

### ★ QUALITY OF ACCREDITATION

UK-PIN is keen to ensure it maintains the highest quality, particularly in accreditation. Contact has been made and discussions opened with UKAS to advance this policy.

### ★ GENERIC PROTOCOLS

So far 6 generic protocols based on common practice have been produced and posted on the website for comments for 3 months. The protocol-writing group of nurses and consultants, will reconvene in the autumn to continue adding to this openly available, important database.

### ★ LINKING WITH OTHER ORGANISATIONS IN PID

Liaison with a variety of bodies involved in the provision of PID services has been crucial to provide a way of influencing decision-making within the UK and Europe. These include:

- European Medicines Evaluation Agency
- Individual immunoglobulin manufacturers & the Plasma Products Therapeutics Association
- Specialist commissioners in the NHS
- Department of Health
- Joint Committee for Immunology and Allergy of the Royal College of Physicians and the Royal College of Pathologists
- Other professional bodies involved in medical specialities in which IVIg therapy is used.

continued overleaf

## PREVENTING PRICE WARS

The Agency has been concerned, along with UK-PIN, that if products are bought on price alone, some suppliers may choose to leave the UK market. There have been significant and disruptive shortfalls in supply over the last few years. However, the NHS Purchasing and Supply Agency [PASA] has been negotiating with IVIg suppliers on national contracts for cost and volume of supply of IVIg. The aim is to stabilise supply and price, prevent price wars, and allow the Agency to monitor usage more accurately. Trusts can then make arrangements with suppliers knowing there are agreed prices fixed for 12 months to 30th April 2004 with an option to extend. UK-PIN and the PiA are interested in how the process works, and want to hear of any problems that arise. Comments to the office, please.

## SURVEYING COMMISSIONING

Turning specialist service definitions for immunology, allergy and immunopathology into hard resource has been painfully slow. UK-PIN is conducting a survey of Centres to try and understand how well the process has gone around the country. Accurate information will help UK-PIN make representations about the progress or lack of it. It is clear some parts of the country are well advanced with funding flowing to PID Centres from Regional Specialist Commissioning Groups, while in others no progress has been made.

Please give us feedback about what is happening in your area.

## JOB SWAP

UK-PIN has funded one application from a Nurse, for the exchange scheme but this is the ONLY application! Please can we have some more. If we don't have any applications soon, the PiA, which has funded the scheme, will lose interest and use the funds for other purposes.

## CONTRIBUTIONS

Please send any information you wish published to the office. We can put urgent information on the website

## APPLYING FOR GRANTS

A drive to develop collaborative programmes of research in CVID, launched by PiA chairman Clare Tritton at Coughton Court, has culminated in a meeting between the UK-PIN Chairman, Dr. Helen Chapel, Professor Lennart Hammarstrom and Professor Mark Walport of the Wellcome Trust. Although no clear promise of funding was forthcoming and no guarantee of ring-fencing, it is clear that the Trust understands the difficulties of research in small highly specialised fields, and is keen to encourage the submission of grant applications through its normal channels. So the ball is back in our court to get writing those grants!

UK-PIN is keen to foster collaborative research (and the exchange funding might be one way); requests for collaborations can also be posted on the website.

## CONSENSUS

Revision of the Consensus document on antibody deficiency is underway, and a similar but new process has been commenced for hereditary angioedema. The Royal College of Physicians is also interested in the process, such that the resulting documents may be incorporated in their guidelines database.

The leads for the antibody consensus are Amolak Bansal and Mohammed Ibrahim, and the lead for the HAE consensus is Mark Gompels.

## ESID 2004

The next meeting of the European Society for Immunodeficiencies will be held between 21st-24th October 2004 at the Palais des Congres de Versailles in Paris.

The Congress organisers are Agence Albine Conseil. Details from the ESID website: [www.esid.org](http://www.esid.org). The website contains membership details, as well as details of the conference and other activities.

## THE STORY SO FAR: REPORT ON UK-PIN 2000-2003

*continued from page 3*

### ★ LIASING WITH PATIENTS

Six meetings have been held with the PiA patient body to discuss matters of mutual interest. These have included supply and availability of therapeutic immunoglobulin, the relative risk of variant CJD, encouragement of research awareness in PIDs and facilities for supporting outcome databases.

### ★ GOING FORWARD

The organisation plans to continue developing its work in databases, accreditation and in establishing links with other official bodies (see p.1).

Aims for second term 2006-2011 will be decided by incoming officers and steering group.

**Dr. H. Chapel on behalf of the UKPIN Steering Committee  
July 2003.**

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Sponsored by an Educational Grant from Bio Products Laboratory. The views expressed in this newsletter are not necessarily those of BPL

Published by Oyster Healthcare Communications Ltd, Unit 5 Level 6 South, New England House, New England Street, Brighton BN1 4GH  
Tel 01273 601996. Email: [mail@oysterhc.co.uk](mailto:mail@oysterhc.co.uk) [www.oysterhc.co.uk](http://www.oysterhc.co.uk)