

**UNITED KINGDOM
PRIMARY IMMUNODEFICIENCY
NETWORK**

CONSTITUTION

Constitution of the UK Primary Immunodeficiency Network

Purpose

The UK Primary Immunodeficiency Network (UK PIN) is a multidisciplinary organisation devoted to those primary immunodeficiency (PID) disorders included within the specialist definition of Clinical Immunology – definition 16 (approved by the Department of Health). These relate to all primary immunodeficiencies, including disorders of innate and antigen-specific immunity.

Aims:

The principal objectives of the Network are:

- i) To improve the care of PID patients through the development of common approaches to diagnosis and management, by means of setting consensus standards.
- ii) To provide help in the form of generic guidelines based on common practice.
- iii) To influence decision-making processes within the UK and Europe, through representation on behalf of doctors, scientists and nurses working in the field of PID.
- iv) To liaise with the Primary Immunodeficiency Association (PiA), the national group representing PID patients, and with other local groups or national organisations who wish to interact.
- v) To introduce an accreditation scheme to measure compliance with care standards.
- vi) To improve knowledge of PID disorders through facilitation of research, including collaborative databases and new methodologies, and through exchange of information between members.

Members

All nurses, scientists and medical practitioners in the United Kingdom who are involved in the healthcare of patients with primary immune deficiencies or research into these diseases are eligible to be members of UK PIN. Individuals are asked to apply for membership of the Network and to agree to the conditions of membership on an active and opt-in basis. Membership of UK PIN may be available, on request, to relevant professionals working outside of the United Kingdom. Any such requests will be individually assessed on the basis of the applicants professional status and involvement in the field of PID. At present, there are no fees charged for membership of UK PIN. Members will be involved in consideration of any significant, future changes to the component funding of the Network and its activities.

A list of all members is held in the UK PIN office and will be posted on the membership section of the website with the permission of individual members.

All members are eligible to be members of the Network Steering Group.

Organisation

In order to establish effective governance and to ensure operational sustainability of UK PIN a Steering Group is established as the administrative and principal decision

making body with the following executive officers elected by ballot of the Network membership: Chairman, Secretary and Treasurer.

The Steering Group establishes Working Groups, as required, to deal with specific issues such as guidelines, industry liaison, protocol writing, accreditation and database selection. Membership of these groups has depended on volunteers for specific tasks and to ensure balanced representation.

UK PIN has an office established in the Department of Immunology, Royal Victoria Infirmary, Newcastle upon Tyne, with a part time clerical officer. The official website of UK PIN may be found at www.ukpin.org.uk

Executive Officers:

The remit of the officers, periods of office, processes for succession, responsibilities for communication with the Steering Group and membership and with official bodies (such as Royal Colleges, Association of Clinical Pathologists, British Society for Immunology) have been formulated, with the following recommendations:

- terms of office to be 4 years.
- current officers demit in turn; commensurate with their time served, for continuity.
- no formal representation from other official bodies but strong links to be maintained.

The responsibilities of the officers are established and can be found on the website.

A call for nominations to executive positions is made by e-mail to all members, with resulting nominations being circulated and voting undertaken by e-mail or post. The outcome of the election process is decided by simple ranking of candidates on the basis of votes cast by members. Duties of these posts are ratified by the membership prior to election of new executive officers. Results of the voting process are indicated and ratified through the biennial Forum following any election process.

Steering Group

The Steering Group meets at least twice a year. Additional telephone conferences of the Executive Officers to conduct UK PIN business are arranged as necessary. The Steering Group or its officers also meet jointly with representatives of the PiA twice a year, to discuss matters of mutual interest. These meetings may be coincident with meetings of the Steering Group, at the discretion of the Chairman. Minutes are taken and circulated to Steering Group members and are posted on the website for access by members and the PID community. Membership of the Steering Group is indicated in *Appendix A*.

The remit of the Steering Group is to decide policy, to approve and direct actions taken by members of the executive, to receive reports from the working groups and to discuss matters of mutual interest with the PiA trustees.

The Steering Group produces reports, information, guidance or position statements which are available on the website or may be circulated by e-mail and/or discussed at the Immunology Forum. Information is also made available to the membership through the Newsletter on the website.

Membership of the Steering Group is normally for 4 years and is approved by the Annual General meeting at the biennial forum. Members do not normally serve after retirement from NHS practice. There is no formal representation of the related professional bodies. Volunteer individuals are co-opted by the Executive for their specific expertise, as needed for particular projects or for reasons of ensuring broad representation of the spectrum of practice through out the UK (geographical locality, professional status, differing models of service provision). A balance of members of the following bodies is however sought at present: Royal College of Paediatrics and Child Health, Royal Colleges of Physicians, Royal College of Pathologists, Royal College of Nursing, Association of Clinical Pathologists, British Society for Immunology, British Society for Allergy & Clinical Immunology.

Affiliation

Currently, UK PIN is an entirely volunteer organisation, ratified by the open biennial Immunology Forum. The Network is a stand-alone organisation but has been formally approved by the Council of the Association of Clinical Pathologists. The Chairman of the ACP Immunology Committee is an *ex officio* member of UK PIN steering committee. Future affiliations, formal or informal, with other organisations may be sought by UK PIN to the benefit of patients with primary immunodeficiency disorders, the Network membership and the reciprocal benefit of the clinical immunology and larger scientific Immunology communities in the UK. Such arrangements may allow for UK PIN to progress its aims independently or within the context and structure of another professional body, where this may be appropriate.

Funding

UK PIN is supported entirely by commercially sourced, sponsorship income which covers the administrative expenses of the organisation. Additional income may be generated from educational activities. Continuing and new sponsorship is sought on an ongoing basis but the Network aims only to raise funding on a break-even basis to cover operational expenditure. Financial decisions, probity and auditing of the accounts are the responsibility of the Treasurer, in conjunction with the Chairman and Secretary.

Funds raised from any source may be used by UK PIN for the following purposes:

- i. Administrative costs necessarily incurred in the routine activities of the Network, including office staff and infrastructural expenses.
- ii. Development and maintenance of the UK PIN website, including webmaster expenses.
- iii. Steering Group activities.
- iv. Activities of Working Groups established by the Steering Group.
- v. PID centre accreditation activities including training.
- vi. Dissemination of information from the UK PIN office to Steering Group and Network members.
- vii. Exchange of staff between centres for educational/development purposes (utilising designated, specific funds only).

Separate accounts are established to underpin a) the day to day activities involved in the operation of the Network and b) the holding of the biennial Forum.

Accreditation Committee

The accreditation scheme is in the second phase of pilot development. The standards and the guidance, which have been revised in the light of experience to date, are posted on the website. Review of the Standards will be ongoing.

An Accreditation Committee accountable to the Steering Group was formed in 2004 with responsibility for matters relating to the standards and accreditation of PID Centres. This Committee will deal with accreditation applications, assessment visits and appeals resulting from the assessment process in a confidential manner.

Guidelines

A guideline writing group has been set up within UK PIN. The group is responsible for development and review of guidelines relating to diagnosis and management of PID disorders which are posted on the website for consultation. Comments are invited on the structure and content of all guidelines and should be sent by e-mail.

Registry Committee

A Registry Committee accountable to the Steering Group and responsible for matters relating to the UK database developed as a UK-based facility modelled on the ESID database and funded by the PIA was established in early 2008.

Immunology Forum

UK PIN organises a biennial educational meeting for members and other interested parties. An Organising Committee is set up to plan the programme and is accountable to the Steering Group.

Newsletter

UK PIN provides a web-based Newsletter to members on an intermittent, as-required basis. An appointed Editor, who is a member of UK PIN, undertakes the functions of collating submitted articles and organising the Newsletter. The Editor is accountable to the Steering Committee.

The Editor of the UK PIN Newsletter is responsible for liaison with the webmaster in respect of the posting of the Newsletter.

Website

A website (www.ukpin.org.uk) is organised by UK PIN with responsibility for the maintenance of the site delegated to a webmaster, who is accountable to the Steering Group. The website provides information about UK PIN activities, events, contact information and links to other relevant websites. Information posted on the website will be approved by the one of the Executive post-holders of UK PIN, normally the Secretary.

Policy

Policy for UK PIN is formulated by the Steering Group, or by one of the sub-committees, in which case formal endorsement by the Steering Committee is sought. Post holders may take executive action in the name of UK PIN but are required to account for these to the Steering Group and thence to the PID community via the website and Forum.

The Constitution is reviewed annually by the Steering Group and ratified by the members every 2 years. This is next due in 2009.

Liaison with other bodies

The Steering Group considers all requests for liaison with other bodies, and will delegate an individual member to take the necessary action to ensure effective liaison. He/she will report outcomes to the Steering Group and thence to the PID community via the website.

Constitution

The details of the Constitution are available at all times on the website and are circulated to all UK PIN members prior to the biennial Forum. Opportunity for members to openly raise issues relating to the Constitution, and to formally ratify the Constitution, will be made within the programme of the Forum. Any changes to the Constitution which are necessary in the intervening period will be notified in advance to members via the website.

UK PIN Steering Group 2008

Appendix A

Steering Group (April 2008):

OFFICERS	Demit Date
Phil Wood (Chairman)	2012
Carrock Sewell (Secretary)	2008
Dinakantha Kumararatne (Treasurer)	2009
MEMBERS	
Bodo Grimbacher	2010
Terry Flood	2010
Matthew Helbert	2009
Jackie Moor	2010
Lucia Russell	2009
Joe Unsworth	2009
Cathy Cale	2012
<i>ex officio</i>	
PiA Medical Advisory Panel Chair (Aarn Huissoon)	2010
PiA Chief Executive	-
Chair, ACP Committee on Immunology (David Edgar)	2010