

UK-PIN GUIDELINES: YOUR VIEWS NEEDED

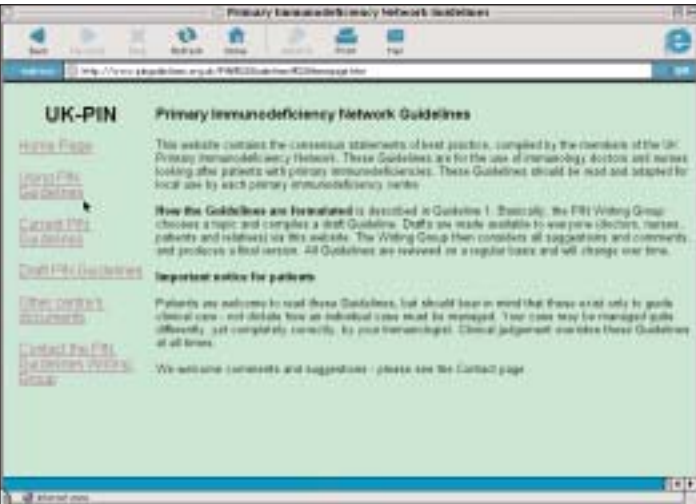
Matthew Helbert

At the York PIN meeting in 2001, a group of Immunologists and Specialist Nurses volunteered to develop a pool of guidelines for use by PID centres. The group has met on several occasions and developed a process for writing guidelines.

We have found that the small writing group (myself, Cathy Cale, Cilla Freud, Caroline O’Grady, Carrock Sewell, Phil Wood) has worked reasonably effectively up to now. For the time being, we do not plan to change the membership. We will seek help from other individuals in writing specific guidelines over the coming months.

The guidelines are not proscriptive in any way. Those of us who have undergone the PIN accreditation process are aware of the hard work involved and our main aim in writing this material is to give other centres a basis on which to write local protocols. Writing guidelines also highlights areas that need to be addressed by national audit or multi-centre research. Our guidelines will not be used by PIN to assess centres undergoing the accreditation process.

The first step was to identify areas that needed specific guidelines – our initial list identified over 30 such topics (see box). A writing group member then took ownership of a specific topic and developed the guideline, using published guidelines and existing material



The draft guidelines will be posted at <http://www.pinguidelines.org.uk/>

UK-PIN GUIDELINES UNDER DEVELOPMENT

- Intravenous Ig replacement
- Subcutaneous Ig replacement
- Consent and evidence of information given for Ig patients
- Monitoring (inc serum saves, LFTs, HCV, CT/RFTs)
- Transient hypogammaglobulinemia of infancy
- CVID diagnosis
- CVID management
- Adverse event monitoring
- Individual annual risk assessments
- Subclass/specific antibody deficiency diagnosis
- Subclass / 'specific antibody' deficiency management
- Home therapy
- XLA diagnosis
- XLA management
- Genetic counselling and consent
- HIGM diagnosis
- HIGM management
- IgAD diagnosis and management
- Recurrent boils management
- SCID initial management
- SCID diagnosis
- Di George diagnosis and management
- Immunodeficiency registries
- Antibiotic prophylaxis for patients not on Ig
- On going antibiotics for patients on Ig
- Holding courses of antibiotics at home
- HAE diagnosis and management
- Complement deficiency diagnosis and management
- Bronchiectasis
- Mycoplasma arthritis

from PID centres. Medline searches were also carried out to seek evidence for each guideline. Draft guidelines are reviewed by the group and amendments made as required. For many topics there is little in the way of randomised clinical trial evidence. We have tried to reflect these uncertainties in our draft guidelines. At the same time, we are trying to keep each guideline concise and where there is controversy surrounding a topic, readers will be guided to review texts (when these exist!).

It is likely that individual clinicians and nurses are aware of evidence that we have been unable to unearth. Others may have anecdotal experiences that we don’t know about. We would like to incorporate this type of knowledge in our guidelines and would value input from the primary immunodeficiency community as a whole. The draft guidelines will be posted at <http://www.pinguidelines.org.uk/>. Everyone is invited to send comments to the guideline writing group. These will be forwarded to the author who will try and incorporate them whenever possible. We will be pleased to receive comments from nurses, clinicians, patients and, even, managers. But please note that if the response is at all overwhelming, we won’t be able to respond to each comment individually.

You will find two other resources on the website. The first is a list of guidelines we plan to develop and our expected deadlines. We also hope to post, or publish links to, guidelines that have already been developed by individual PID centres. PIN members may find

Welcome to the Spring issue of the UK-PIN Newsletter. As usual we are grateful to BPL for their continued sponsorship of this newsletter.

We are very keen that everyone should look at and feedback on the Guidelines [see the article by Matthew Helbert on page 1]. So far [as of 11th March] there has not been a single piece of feedback! These are going to become the recommendations for management of PIDs, so we want everyone to have their say.

We will be establishing a website shortly and you will be able to access documents such as the guidelines and the standards. Application forms will also be accessed through the website [thanks to Carrock Sewell for making this possible].

We are also keen to see more articles for the newsletter from outside the editorial and steering group teams: if you have something to say send it to me! Letters are always appreciated!

Gavin Spickett
Editor

SAFEGUARDING LONG TERM IMMUNOGLOBULIN SUPPLIES TO THE UK

Dr. Alison Jones, UK PIN Industrial Liaison Officer

In December 2002 the Department of Health made a decision to purchase the largest remaining independent US plasma collector, Life Resources Incorporated. This is a very welcome move, which will help to ensure that availability of plasma products for NHS patients will not be compromised by the current global plasma shortage.

The US is the largest worldwide collector of plasma, supplying approximately 60% of the world's plasma, and 35-45% of plasma products used in Europe. NHS-owned Bio Products Laboratories, who manufacture and supply approximately 45% of NHS plasma products, has been using US-sourced plasma as part of the UK vCJD risk-reduction strategy since 1998. Each year in the UK approximately 2000 kg of intravenous Immunoglobulin is currently required for patients with primary immunodeficiency.

Life Resources, who have supplied plasma to BPL since 1999, is a group of 27 affiliated US companies with 24 plasma collection centres across the US and headquarters in New York. Quality and safety standards are overseen by the US FDA and the UK MCA, and collection centres are inspected on a two year rolling programme by BPL's Quality Audit Team. A long-term contract has now been signed between Life Resources and BPL to supply BPL with plasma.

This decision by the DoH is clearly welcome to immunologists and to the Primary Immunodeficiency Association in the light of recent concerns about the continuity of plasma supplies to the UK. Companies other than BPL have recently been reassuring about their ability to maintain

their current level of Immunoglobulin supply to the UK, but the difficulties generated by the diversion of Sandoglobulin supplies to the US with little warning several years ago must inevitably make us wary of such confident predictions.

IMMUNOGLOBULIN ANNUAL USAGE REGISTER

The UK-PIN Industry Liaison Group is in the process of setting up a register of annual Immunoglobulin usage by Immunology centres throughout the UK, which will be used to predict the needs for the subsequent year, and each company will be asked to confirm their ability to maintain supply for that period. This will hopefully help to ensure continuity.

Despite this welcome move, there is nevertheless a need for even longer-term strategies to ensure maintenance of supplies. Most patients with primary immunodeficiency have no prospect of an alternative to Immunoglobulin therapy, and although the purchase of Life Resources will increase security of UK supply for the medium term future, it will be important to seek mechanisms to reduce the heavy reliance on the US by increasing plasma collection within Europe, possibly including more use of apheresis and increased donor compensation.

**PIN IMMUNOLOGY FORUM
7-8 NOVEMBER 2003
YORK**

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IMMUNOLOGY AND ALLERGY NURSES GROUP - ANNUAL MEETING REPORT

Lisa Wright

A big thanks to everybody at Great Ormond Street Hospital for organising an excellent meeting and to Carl Wheeler from ZLB for the sponsorship.

Immunology Course

The future for a course specific to Immunology looks more promising. Peter Vickers and colleagues in conjunction with Hertford University have been very busy developing a distance learning package which can be undertaken at either MSc or Masters level. The course should be validated in March 2003 and is hopefully due to start in September 2003. Any one interested should contact Peter Vickers via email p.s.vickers@herts.ac.uk. Places are limited to 10 - 15 students per year. The enrolment fee is expected to be £495 per module. The examination process will be via written assignment and oral presentation. Further information about the course can be obtained from the Hertford University website.

Secretary

Jackie Hobbs will be standing down as secretary to the RCN Immunology and Allergy Nurses Group. She has served her two year sentence. Anyone wishing to take on the role should speak to Jackie or John Toolan for information as to what is entailed. Please consider this and it can be discussed further at York.

Reminder

The PIN Immunology Forum is taking place in York again this year. The dates are November 7th and 8th. Unfortunately due to a change in sponsorship there will be a small fee. The nurses' fee has been substantially reduced due to some very generous sponsorship from BPL. The fee will be £75 and this will include the two day conference with lunch and refreshments, evening dinner (Fri 7th) and overnight accommodation in the Royal York Hotel. There will also be a prize for the best poster submitted by a Nurse and it would be nice to see an increase in the number of posters entered this year.

Immunology Nurses in Scotland

Donna Hood (Creran) Immunology Sister in Glasgow has unfortunately left her post in Glasgow. Everyone in the RCN Immunology Nurse Group wishes her the very best of luck in her new post. At present this leaves Scotland depleted of nurses until the post is filled. Phylis Nichol is currently the only nurse in Scotland and we as a group will endeavour to support her in whichever way we can.

The RCN Immunology and Allergy Nurses meeting also consisted of a number of excellent talks by external speakers. The first talk woke us all up to the reality of what happens to the documentation we keep or don't as the case may be should we have to face a law suit. I'm sure that I



External speakers prompted questions and debate at this year's meeting

wasn't the only one questioning my level of documentation during that lecture. An excellent talk was given by a radiologist from GOS. He showed x-ray films and CT scans of Immunology patients with different degrees of lung disease.

Finally the meeting gave everyone the opportunity to say a fond farewell to Nicky Brennan from Oxford. Nicky will be retiring very soon and was the first Immunology Nurse in the U.K. We all owe her a great dept of gratitude for her support and wealth of knowledge she has passed on to us all one way or another. She will be an enormously missed, not only by the nurses. I am sure it will be even harder for her patients. Good Luck Nicky.

CONSULTANT IMMUNOLOGIST REQUIRED

There is a new post for a Consultant Immunologist to head the Department of Immunology in Ninewells Hospital, Dundee.

The laboratory serves a population of approximately 500,000 and the consultant would be responsible for the laboratory service and a clinical Immunology service for patients with anaphylaxis and severe angioedema, and also patients with primary immunodeficiency disorders.

Good opportunities exist for under- and post graduate teaching and for research, links with Molecular and Cellular Pathology in the Medical School on site and also the main University of Dundee campus in particular The Wellcome Trust Biocentre.

Dundee is situated on the north bank of the river Tay surrounded by lovely countryside. The standard of living is high and the cost of housing low compared with other areas. There are good transport links with the rest of the UK .

Enquiries to Dr Elizabeth Spiers
Telephone: 01382 632534

UK-PIN IMMUNOLOGY FORUM, 7-8 NOVEMBER 2003, YORK

The provisional programme for the meeting has now been agreed by the steering committee and appears below. This is still subject to change, depending on confirmation from speakers and chairmen. Invitations will shortly be despatched by AdOration to all on the UK-PIN mailing list.

The meeting has generous sponsorship from the companies [BPL, Octapharma, Grifols and ZLB], and in particular BPL will be subsidising the registration and accommodation costs for nurses. We could still do with more sponsorship, so if you have good contacts with other companies please encourage them to contact the office.

Poster prizes will be offered again for the trainees and nurses [supported by Octapharma and BPL], so please get thinking. Details of the poster requirements will be sent with the registration documents.



UK-PIN returns to York this year - a venue popular with members

PROVISIONAL PROGRAMME:

Friday, 7th November

10.00 am	Coffee & Registration
10.25 am	WELCOME & INTRODUCTION
	CLINICAL MANAGEMENT & PROTOCOLS:
10.30 – 11.00 am	C1-esterase Inhibitor Deficiency
11.00 – 11.30 am	Long-Term Follow Up of Transplantation for SCID
11.30 – 12.00 pm	C40 Ligand deficiency (Adult) versus Paediatric Transplant followed by Discussion
12.00 – 12.30 pm	What is CVID?
12.30 – 2.00 pm	Lunch, including Poster Viewing Judged by Scientific Committee:
	CLINICAL MANAGEMENT & PROTOCOLS (cont.):
2.00 – 2.30 pm	Extended and Supplementary Nurse Prescribing
2.30 – 3.00 pm	Adverse Reactions to Immunoglobulin
3.00 – 3.30 pm	Anaphylaxis and the Use of Epipens
3.30 – 4.00 pm	Tea
4.00 – 5.00 pm	CASE PRESENTATIONS AND POSTERS:
	Diagnostic Dilemmas: Case Presentations by Trainees and Nurses (preselected – 10 min presentations with 5 min discussions, 2 from Trainees & 2 from Nurses)
5.00 – 6.00 pm	Poster Presentations by Trainees and Nurses (preselected – 10 min presentations with 5 min discussions, 2 from Trainees & 2 from Nurses)
7.30 pm	Reception
8.00 pm	Dinner including presentation of poster prizes

Saturday, 8th November

9.00 – 9.30 am	SCIENTIFIC SESSION:
9.30 – 10.10 am	Immunotherapeutics
10.10 – 10.30 am	Cytokine Signalling Deficiency
10.30 – 11.00 am	Update on Gene Therapy for PIDs
	Thymic Development
11.00 – 11.30 am	Coffee
11.30 – 1.00 pm	PRACTICE ISSUES:
11.30 – 11.50 am	Immunoglobulin Supply and Industry Liaison
11.50 – 12.10 pm	Bronchiectasis Protocol and Liaison with BTS
12.10 – 12.30 pm	Progress of Guidelines for Management of PIDs
12.30 – 12.50 pm	Accreditation and Standards Update
12.50 – 1.00 pm	Question and Answer Session on UK-PIN Annual Report (circulated in delegate pack)
1.00 – 2.15 pm	Lunch
2.15 – 2.35 pm	DIAGNOSTIC TESTING:
2.35 – 2.55 pm	Problems with Specific Antibodies
2.55 – 3.25 pm	Standardisation of Cellular Function Assays
3.25 – 3.45 pm	Preimplantation Diagnostics
	Diagnosis of Rare Primary Immunodeficiencies (protein and genetic tests)
3.45 – 4.00 pm	Summary of Meeting
4.00 pm	Close of Meeting

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