Acknowledging contribution to surveillance studies

The Vancouver Protocol (www.icmje.org) provides clear criteria for authorship and the acknowledgment of contributions to scientific publications. However, contributors to health surveillance research, who make such research possible by the identification of cases and the provision of clinical data, have questioned the applicability of these criteria. The International Network of Paediatric Surveillance Units (INoPSU) (www.inopsu.com) is an international association now including 14 national paediatric surveillance units (PSUs) that conduct active surveillance of a range of uncommon conditions of childhood, including infectious and vaccine preventable diseases, childhood injury, and genetic and mental health conditions. Over 7000 child health specialists, many of whom report on behalf of their colleagues or departments, contribute cases to the PSUs on a monthly basis. The population covered is approximately 54 million children under 15 years of age.

Clinicians who report a case to a PSU are asked to provide additional clinical and demographic details to study investigators. Some surveillance studies have significant workload implications for individual clinicians. Although most clinicians will not see a child in any one month with one of the rare conditions under surveillance, a high return rate of the “nil to report” response underpins the quality of the PSU active surveillance mechanism.

At the 3rd meeting of INoPSU in Lisbon in April 2004, the following guidelines on authorship and acknowledgment were proposed for recommendation to investigators conducting epidemiological research through the PSUs:

- To qualify for authorship on reports, individuals must fulfil the Vancouver criteria. However, in acknowledgment of their essential contribution to the work, the addition of the statement “on behalf of contributors to the (national PSU)” following the final author’s name is encouraged.
- Investigating teams are encouraged to consider inviting clinicians who have contributed significant data (through notifying cases) onto the study team. These clinicians may have expertise relevant to the analysis or reporting process. Report authorship may then be assigned if appropriate according to the Vancouver Protocol.
- Report authors should consider naming clinicians who have contributed significant data in the acknowledgments section of the report, according to the Vancouver Protocol. Report authors are reminded that the Vancouver Protocol requires that permission must be sought to acknowledge individual clinicians by name.

INoPSU member units will provide these guidelines and a copy of the current version of the Vancouver Protocol to each investigating team conducting research through the PSUs, preferably prior to the commencement of the surveillance study. These recommendations may also be applicable to the reporting of other research requiring the provision of clinical data from multiple contributors apart from the study authors.

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On behalf of members of the INoPSU (Portuguese PSU), German PSU, and INoPSU Convenor, Australian PSU

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References

BOOK REVIEWS

Pediatric endocrinology: the requisites in pediatrics


Studying paediatric endocrinology is like staring into the waters of Loch Ness. In the cold light of a Scottish day it is possible to see a few inches into the murky depths, and while most visitors are comfortable seeing the loch’s surface, to consider plumbing the dark waters gives one an eerie feeling about what could lie beneath (encouraged by the locals). Like the mythical monster, the rarer syndromes are often the subject of fragmented case reports, discussed using apocryphal stories (in darkened rooms using faded slides), yet to catch them in the wild needs both an inquisitive mind, an awareness of what one could be hunting for, and the investigative equivalent of a big submarine with echo-location sonar.

This book aims to support paediatricians, paediatric trainees, and paediatric endocrinologists alike and aims to update the clinician on current management and current research developments in paediatric endocrinology (that is, to act as a lifebelt if you’re adrift on the loch and screaming for help). “Requisites” is defined here as the “basic knowledge that is necessary for practise or board review” and aims to provide knowledge up to the level of a tutorial rather than aspiring to be a reference text or source book. The authors also designed their chapters to maintain a clinical focus. There are seven sections: Carbohydrate Disorders; Sexual Development; Growth; Thyroid; Adrenal Gland; Calcium, Phosphorus, and Bone; and Vasopressin and Disorders of Electrolytes.

Have the authors succeeded with this lifebelt? I believe they have gone a long way to helping the clinician manage common clinical scenarios (such as the hypoglycaemic neonate and type 1 diabetes). Tables and “major points” boxes highlight the key features to be drawn from each chapter. Colour photographs are also grouped at the front of the book, but could be better placed, either incorporated with the relevant text, or have references in the text linking the pictures appropriately.

There is also a useful integration of current research to refresh oft-said information that is readily available in older texts. This provides clinicians with a gauge of current academic thinking, for example important genes in pubertal delay (e.g. leptin), and there is certainly enough detail for consultants wanting to keep one step ahead of enthusiastic registrars, fresh from their membership exams.

The recent proliferation of cases of type II diabetes is also discussed, drawing on extrapolated experience from current paediatric diabetic practice, and adult type II diabetes, while the evidence base develops for management of paediatric type II diabetes. There is a good explanation of the diagnostic features, and their differences from type I diabetes, and management includes good practical advice to parents regarding weight loss, exercise, and reducing TV watching.

All the chapters brought new depths to my understanding of paediatric endocrinology. However, as with other American textbooks, the glucose is measured in mg/dl not mmol/l, and providing a conversion would have helped those clinicians using mmol/l (N.B. mmol/l x 18 = mg/dl). Also there is no mention of aspects of paediatric endocrinology specific to the UK, for example NICE (National Institute of Clinical Excellence) guidelines on the use of growth hormone.

There are some paediatric tomes on paediatric endocrinology that are as likely to help you sink faster, with their weight of information, as they are to bring you to the distress, and some that are too light and miss out essential information. This however is an excellent resource to access for the clinician in difficulty, is well worth the money, and would be a good lifebelt to choose.

M P Tighe
In their preface to this roughly 200 page book, which chronicles the Cambridge Prader-Willi syndrome (PWS) study, the authors Tony Holland (Chair in Learning Disabilities) and Joyce Whittington (Senior Research Assistant) describe their study as “a process of discovery that included getting to know many people with Prader-Willi syndrome and their families”. Following a thorough and painstaking process of identification and ascertainment, the authors managed to identify 96 patients within the Anglia and Oxford Health regions in whom the diagnosis of PWS was secure. Both the birth prevalence (1 in 20 000) and population prevalence (1 in 50 000) to be calculated. The authors then carried out home visits with completion of a detailed semi-structured questionnaire in 61 of these patients. A further 42 PWS patients from outside the study area were studied as were 32 subjects with learning disability who did not have PWS. The information gathered was used to determine predictive features for diagnosis, the behavioral and cognitive phenotypes, and the incidence and nature of psychiatric disorders.

The combination of rigorous diagnostic ascertainment, detailed first hand information, and thorough analysis make this a landmark study. The book is well written, the authors beginning with a succinct description of various aspects of PWS, including the genetic neuroendocrine, safety, sleep, temperature, and learning abnormalities. The genetic and neuropathology sections are particularly commended for being intelligible to readers with little knowledge in these fields.

Only a brief mention of some of the study findings can be given here. Ninety nine per cent of patients with PWS can be diagnosed correctly if all four of the following features are present: floppy at birth; weak cry/inactivity in infancy; poor suck at birth; and chronic constipation. Psychometric testing confirmed a roughly 40 point downward shift in global IQ. Patients with disomy (inheritance of two maternal chromosomes 15 and hence loss of the paternal contribution in the critical 15q11–13 region) showed higher verbal abilities than patients with PWS caused by a deletion on the paternal chromosome 15. Disappointingly, perhaps, the celebrated ability of PWS individuals to complete complicated jigsaw puzzles did not relate to enhanced ability and probably reflects plenty of practice related to the repetitive behaviour patterns of the condition! A striking feature was the prevalence of psychotic illness in older patients. After the age of 28 years, 7 of 15 patients had experienced a major psychotropic episode. This included all of the five patients with disomy. This latter finding, which has considerable therapeutic implications, calls for further research.

This book is compulsory reading for anyone with a serious interest in PWS—I have ordered a copy for each member of the Yorkhill multidisciplinary Prader-Willi Clinic! Those seeking more information on this fascinating and elusive disorder will find plenty of fascinating information to dip into. Anyone attempting to write a paper about PWS will be greatly helped by the numerous references given and the intelligent discussion that accompanies them.

M Donaldson

Physiological and pathological auxology


Auxology, for the uninitiated, is the study of growth. This large book aims to cover exactly what it says in the title: normal growth and how to measure it, and abnormal growth secondary to illness. It is a multi-author text (n = 67), mainly with European contributors, and is edited by a well respected Italian team. The nearest book in scope would be the classic Faulkner and Tanner three volume treatise Human growth, last published in 1986. Thirty per cent of the book concerns the physiology of growth and body composition, how to measure children, the construction of reference standards, and normally. Sadly there is little on the assessment of the inter- and intra-observer accuracy of various measurements that would have been useful for those involved in designing growth studies. The largest, middle portion of the book relates to the growth patterns associated with a list of disorders. There is an uneasy tension between concentrating on pathological growth in, say, thalassaemia to the exclusion of other clinical and treatment details, which are not uniformly tackled by each writer. Although fairly comprehensive in scope, some major causes of poor growth that would be a common referral to an endocrine unit are hardly mentioned. One would have to consult other texts for more clinical information after reading many of the chapters. It would have been useful to include reference charts of growth in the skeletal dysplasia in particular, which chapter is largely based on radiographs. The final part of the text deals with social and epidemiological aspects of growth and an eclectic number of national charts are given as an appendix.

Like all multi-author texts there is inevitably a variation in the quality of the content. Some important recent developments in auxological technique and growth studies are ignored altogether. However, some chapters are completely current and well written and deserve a wider audience. One huge 40 page chapter in a rapidly expanding field has no references more current than the late 1990s and feels dated. This sensation is reinforced by the historical nature of some of the illustrations that date from the middle of the last century and are of poor quality, and an unusual font and layout throughout which is reminiscent of typewritten dissertations of the pre-word processing era.

This is a reference book that belongs in libraries of large units with an interest in growth related research or regional endocrine centres. There is little that would appeal to a more general reader without these specialised needs.

J K Wales