

Atoms



Howard Bauchner, *Editor-in-Chief*

A UK GEM – THE BRITISH PAEDIATRIC SURVEILLANCE UNIT

Since my formal training is in epidemiology and biostatistics, the British Paediatric Surveillance Unit (BPSU) has been an important source of information for me. It is a gem of the UK paediatric research community. It provides among the best data on rare diseases in the world. In this issue, Richard Lynn and Euan Ross provide a 20-year perspective on the BPSU. They review its history and achievements, including a number of landmark studies, as well as the development of the International Network of Paediatric Surveillance Units, a group of 12 other surveillance programmes.

As part of our celebration of the BPSU we have included two important papers from the unit – one in *ADC* and the other in *F&N*. The first report repeats a survey, using the same methodology previously employed by the BPSU that focuses on vitamin K deficiency bleeding. Surveys had been conducted in 1993–94 and 2001–02. It appears that the incidence of vitamin K deficiency bleeding has more than halved since the previous two reports. The second study focuses on the incidence of bilirubin encephalopathy – kernicterus – in the UK. In a study conducted over 2 years, the incidence of severe hyperbilirubinaemia (maximum unconjugated bilirubin $\geq 510 \mu\text{mol/l}$) was 7.1/100 000 live births and the incidence of bilirubin encephalopathy was 0.9/100 000 live births. Given the renewed interest in breast feeding around the world, and the apparent increase in kernicterus in some countries, these data are likely the best that will ever be generated. My compliments to the authors of these two papers and of course to the BPSU.

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ETHICAL DILEMMAS IN PAEDIATRICS

Numerous ethical dilemmas arise in the care of infants and children—for example, end-of-life decisions, particularly for neonates. I think, for the better, many of

these issues are now discussed and debated quite openly in the press and on the internet. Since research in these areas is often qualitative, and rarely offers definitive information that can direct decision-making, under the leadership of Patrick Cartlidge, our Deputy and Commissioning Editor, we have tried to use our leading article section to highlight complex and controversial questions. Robin Powell, in an articulate and detailed paper, reviews the dilemmas in the treatment of “children facing inevitable death.” Although the vast majority of decisions in the US and UK regarding end-of-life are made in confidence between parents and a healthcare team, ultimately, in the US, parents retain the legal right to decide. This is decidedly different than in the UK, where physicians cannot be compelled to treat a child against their beliefs. However, there have been a number of very public cases in the past few years that have challenged this assumption.

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FOOD ALLERGIES – INCREASING OR REPORTING BIAS

There is some belief that food allergies are increasing. When entering any place where large numbers of infants and young children are cared for, it is impossible to avoid the long list of allergies assigned to many children. Currently, I am involved in an epidemiological study of allergy in full term and premature infants. Following birth, we test infants 2–3 times, over 3 years, for allergy using RAST. About 7% of children have a “positive” test for milk, eggs, etc. Are these children allergic, or simply test positive? Obviously, a definitive diagnosis of food allergy requires more information. Only about half have symptoms that could be attributable to allergy and few undergo skin prick testing. However, some do have the offending food eliminated from their diet. In this issue, Hu and colleagues from Australia, in a qualitative study involving 84 parents of children with food allergy who completed semi-structured interviews, and participated in focus groups, describe the informational needs of these parents. Not surprisingly, parents want more information, in various formats.

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THE RELATIONSHIP BETWEEN MENINGOCOCCAL INFECTION AND NUTRITIONAL STATUS

In a counter intuitive paper from Argentina, Perez and colleagues report that severe meningococcal infection in 127 children was related to nutritional status. Interestingly, better nutritional status, as assessed by weight for age, height for age, mid-upper arm circumference and body mass index, increased the likelihood of both severe disease and death. The authors dismiss the likelihood of referral bias, since their hospital is situated near the most populated referral areas. I am less sure, since they provide no information about children dying at home or in other settings. They provide numerous explanations for their findings, including the possibility that better nutritional status may lead to an exaggerated inflammatory response, which in turn leads to more severe disease.

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THIS MONTH IN FETAL AND NEONATAL EDITION

- Infant mortality is used to compare healthcare systems. In a study comparing Trent and Nord Pas-de-Calais, it appears that more very premature infants are classified as live-born in Trent, impacting on infant mortality figures. See page F356
- Medical errors have become an important focus for healthcare systems. In a report from The Netherlands, Snijders and colleagues, in a methodological review of 10 studies found that voluntary reporting rather than mandatory reporting led to higher total error rates. See page F391
- Iron deficiency remains the most common nutritional deficiency in the world. Even in the UK and US about 20% of impoverished infants are iron deficient at 1 year of age. Verner and colleagues report that maternal diabetes increases depletion of fetal iron stores. See page F399