

EDITORIAL

PRES GUIDELINES FOR PEDIATRIC RHEUMATIC DISEASES

At the founding meeting of the Pediatric Rheumatology European Society (PRES) in Glasgow, Scotland in 1999, the general assembly elected a council member responsible for clinical affairs with the explicit directive to establish guidelines for the most prevalent diseases in the field of pediatric rheumatology. The council of PRES supported this project and asked me to prepare them. The aim was to harmonize treatment in Europe, to set a minimum standard of care and to point out the existing (or not infrequently, and more accurately, the lack of) evidence for the present best practice. We appreciate the opportunity to publish these guidelines in PROJ.

Instructions on development of these guidelines were established including a uniform format that benefited from the recent experience of the German pediatric rheumatology working group. The guidelines put special emphasis on the practical management of the pediatric rheumatic diseases. They are not meant to be followed explicitly and to the letter in each patient. They are not meant to be used in malpractice litigation. However, the guidelines do attempt to define what the best standard of care is for any one disease and what a minimum standard of care is as recommended by PRES. The guidelines are not meant to be comprehensive and the attending physician is urged to refer to textbooks and other references. So, although they are called by the popular term “guidelines”, it might be more appropriate to refer to them as “recommendations”.

These guidelines are also written for a general audience with a scientific or political interest. This audience might include representatives from governments, insurance companies, political parties, research organizations and other groups. Although parents and patients are very welcome to consult these guidelines, educational material prepared by the Pediatric Rheumatology International Trials Organization (PRINTO) and other resources might be more appropriate for their better initial understanding (www.printo.it/pediatric-rheumatology/).

The following topics were selected for the development of guidelines: oligoarthritis, polyarthritis, arthritis associated with enthesopathy, systemic arthritis, psoriatic arthritis, Lyme arthritis, systemic lupus erythematosus, juvenile dermatomyositis, scleroderma, vasculitides, and episodic fever syndromes. A senior author was appointed to each topic to prepare a draft and members volunteering to contribute were chosen as co-authors according to their particular expertise.

The senior authors wrote the first drafts of the guidelines and then altered them according to the editorial recommendations of the co-authors. This edited draft was then submitted to 5 PRES council members for further suggestions (Rebecca ten Cate, Hans-Iko Huppertz, Isabelle Koné-Paut, Seza Ozen, and Patricia Woo). The revised guidelines were then circulated among other council members. The first 4 guidelines (oligoarthritis, polyarthritis, systemic arthritis, Lyme arthritis) were approved by the council of PRES in 2004 and the other guidelines are in progress.

The present guidelines are the opinion of this scientific society, its members, its council and the editor based on the published literature, textbooks and experience. In spite of extensive revising, these guidelines are recommendations and the attending physician will have to find the best approach to the individual patient including the possibility that one may need to deviate from these guidelines. The guidelines contain scientific information and do not include legal or other regulatory obligations, including licensure of drugs which might have an impact on the management of the patient. In the opinion of PRES, patients should not be denied the treatment as recommended in these guidelines by governments or insurance companies, unless they can express their denial reasonably and in writing.

Pediatric rheumatology is a young science and changes in the standard of practice occur at a rapid pace. Please do not hesitate to send me your comments including proposals for improvement. These guidelines will be updated as scientific evidence accumulates and changes our pediatric rheumatology standard of practice.

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Member of the Council of PRES and responsible for clinical affairs

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