EDITORIAL

Paediatric Rheumatology: Where we are coming from and where we are going

Reumatología Pediátrica, de dónde venimos y a dónde vamos

Jordi Antóna, Marisol Camacho Lovillob,*, Esmeralda Nuñez Cuadros c

a Sección de Reumatología Pediátrica, Servicio de Pediatría, Hospital Sant Joan de Déu, Barcelona, Spain
b Servicio de Infectología, Reumatología e Inmunología Pediátrica, Hospital Universitario Virgen del Rocio, Sevilla, Spain
c Unidad Reumatología Pediátrica, Hospital Regional Universitario de Málaga, Málaga, Spain

Received 8 January 2020; accepted 10 January 2020

In 1483, Sandro Botticelli depicted what may be one of the earliest representations of juvenile idiopathic arthritis (JIA) in “Portrait of a Youth”, in which he showed the swelling of the wrist, metacarpophalangeal and proximal interphalangeal joints of one hand. But it was in 1897 that George Frederic Still, a paediatrician and pathologist at the Hospital for Sick Children at Great Ormond Street, London, published an article describing 22 children with chronic arthritis and highlighting that rheumatic manifestations in children differed from those in adults. Some of these patients had what years later came to be known as Still’s disease and is currently known as systemic-onset JIA. It was not until 1940 that the idea emerged again that children could have rheumatic diseases other than rheumatic fever.

Paediatric Rheumatology is a subspecialty of paediatrics focused on the diagnosis and management of a broad range of diseases: musculoskeletal disorders such as JIA, systemic autoimmune diseases such as systemic lupus erythematosus SLE, juvenile dermatomyositis or juvenile scleroderma, autoinflammatory diseases such as periodic fever, aphtous stomatitis, pharyngitis and cervical adenitis PFAPA syndrome or hereditary periodic fever syndromes, disorders manifesting with increased pain such as fibromyalgia or chronic fatigue syndrome, or secondary osteoporosis, to name a few. To further knowledge in this field, in 1992 a group of paediatricians and rheumatologists in Spain created the Grupo Español de Reumatología Pediátrica (Spanish Group of Paediatric Rheumatology, GERP), which in 1995 became the Section of Paediatric Rheumatology of the Asociación Española de Pediatría (Spanish Association of Pediatrics, AEP) and in 1998 gave rise to the Sociedad Española de Reumatología Pediátrica (Spanish Society of Paediatric Rheumatology, SERPE).

The most frequent chronic rheumatic disease in the paediatric population is JIA, formerly known as juvenile rheumatoid arthritis or juvenile chronic arthritis; JIA ultimately is a consensus-based term that encompasses several subtypes of disease. Few studies have been conducted in Spain to analyse its epidemiology, and a study conducted in Catalonia reported an incidence of 6.9 per 10 000 children aged less than 16 years and a prevalence of 39.7 per 10 000 children aged less than 16 years. On the other hand, it is estimated that 20% of cases of SLE have onset in childhood or adolescence, and most autoinflammatory disorders have onset in childhood. As physicians, we are all familiar with the saying that “one only diagnoses what one knows”, something that is particularly true in the field of paediatric rheumatology. The study published by Udaondo Gascón et al.
in the current issue of Anales de Pediatría corroborates the
perception that training in paediatric rheumatology must be
improved at every level (undergraduate and postgraduate).
It is essential that training programmes for medical stu-
dents, residents in paediatrics and continuous education
include not only information on this group of diseases
but also on the evaluation of the musculoskeletal system.
Nobody would think that it is acceptable for paediatricians
not to know how to examine an ear or perform auscultation
of the chest, but even the most recent evidence today
shows that the physical examination often does not include
a musculoskeletal evaluation and that many medical providers
lack confidence in assessing joints.1,3

Advances in imaging techniques along with the increased
availability of ultrasound technicians in many clinics and in
genetic diagnosis, which guides the management of newly
recognised autoinflammatory diseases, combined with the
development of new treatments, are some of the factors
that have contributed to improvements in the management
of these diseases that we would not even have dreamt
of until a few years ago. Despite advances in treatment,
methotrexate, which has been in use for more than 30 years,
continues to be the main systemic drug used for the manage-
ment of diseases like JIA. For this reason, we consider that
the work of Barral Mena et al. analysing the factors asso-
ciated with adverse reactions to methotrexate, published
in this issue of Anales de Pediatría, is certainly relevant. It
shows that despite its efficacy, up to one third of patients
need to discontinue methotrexate due to adverse effects.4
Fortunately, alternative options are available today, such
as selective immunosuppressive agents (biologic drugs) or
Janus kinase (JAK) inhibitors. The days when children fre-
quently ended up with significant limitations or physical
sequelae, or even dependent on a wheelchair, are behind
us. Today, the vast majority of patients lead normal lives
and participate in sports activities as do children of the same
age.

On the other hand, the follow-up of patients in spe-
cialty clinics has allowed participation in collaborative
networks, registers, studies and clinical trials at the national
and international levels. Institutions such as the Pediatric
Rheumatology Trials Organization (PRINTO), the Pediatric
Rheumatology Society (PReS) or SERPE have invested on pro-
 moting research and the establishment of working groups
to join efforts and progress in the field. In 2013, the Single
Hub and Access point for paediatric Rheumatology in Europe
(SHARE) initiative was launched with the participation of
European paediatric rheumatology networks with the aim
of describing current needs for the optimal management of
children and youth with rheumatic disease.5 This initiative
has given rise to numerous publications in recent years with
recommendations for the management of the most common
paediatric rheumatic diseases, the performance of collabo-
rateive studies or the establishment of biobanks. Particular
emphasis has been placed on the needs of adolescents with
chronic disease and how to facilitate transitioning to adult
care, which often involves a switch in the provider in charge
of the patient.6

We ought to highlight the important and novel role
taken in recent years by patient organizations. For inst-
ance, since 2015 and with the support of the SERPE, a
yearly day-long "symposium for the families of children
and adolescents with rheumatic diseases" is held simulta-
neously in several cities throughout Spain in collaboration
with local patient organizations and the specialists that
manage these patients. In these symposiums, health profes-
sionals, parents and children share experiences, questions
and hopes. Starting this year, this symposium will be held
on March to join the celebration in multiple countries of the
World Young Rheumatic Diseases day (WORD). Furthermore,
some of these organizations make altruistic contributions
to research in paediatric rheumatology, offering research
grants to further knowledge on these diseases.

However, many challenges remain, for instance at the
educational level, since, as is the case in other paediatric
subspecialities, adequate training in the field needs to be
guaranteed. In 1992, the American Board of Pediatrics held
the first paediatric rheumatology subspecialty exam, and in
1994, specialist training was approved in the United King-
dom. Since then, numerous countries have recognised it as
a specialty: Germany, the Netherlands, Italy, France, Aus-
tria, Sweden and Finland, among others. Furthermore, the
European Union of Medical Specialists (UEMS) and its paed-
iatric section, the European Academy of Paediatrics (EAP),
have acknowledged this specialty and the specialty train-
ing curriculum at the European level. Spain should promptly
recognise paediatric subspecialties officially, including paed-
diatric rheumatology.

At the level of care delivery, new communication tech-
nologies must be considered and applied to facilitate access
of patients and their families to the providers involved in
their care. In this regard, specialty nurses and case managers
can play an essential role in contributing to the education,
self-care and follow-up of these patients.

When it comes to research objectives, it is important
to continue to develop new drugs and to conduct trials
with those that already exist, as well as to perform studies
with the aim of identifying biomarkers (genetic, molecu-
lar, indicative of disease recurrence or treatment response)
to aid prognosis and thus guide the selection of appropri-
ate, individualised and targeted treatment, which not only
would increase its effectiveness and decrease the proba-
bility of recurrence, but also improve the adverse reaction
profile.3,8

As health care providers, we must strive to ensure access
to all patients to the best possible care, to specialised care
and to appropriate treatment for their disease. As paedia-
tricians, we should be able to demand from our managers,
coordinators, administrators and politicians that children
with suspected non-infectious arthritis or autoimmune dis-
ease be assessed by a paediatric rheumatologist. There is
still a long way to go, but the subspecialty of Paediatric
Rheumatology is now a reality established on solid founda-
tions.

References
dence and prevalence of juvenile idiopathic arthritis in Catalonia
2. Udaondo Gascón C, Murias Loza S, Alcobendas Rueda R, Remesal
Camba A, de Inocencio Arocena J. Should training in paediatric
rheumatology be improved? Results of a national survey. An Pedi-


