

European Training Syllabus and Programme in Paediatric Rheumatology

Introduction

This syllabus describes the knowledge, skills and attitudes necessary for attaining the title “European Paediatric Rheumatologist” as defined by the paediatric section of the European Union of Medical Specialists (UEMS). It is expected that European paediatric rheumatologists will practice their skills and apply their expertise within the framework of a specialised tertiary care unit, division, department, hospital, or outpatients department. Furthermore, such specialists will have commitment to train general paediatricians, paediatricians with an interest in paediatric rheumatology, rheumatologists and specialist paediatric rheumatologists.

In general this syllabus intends to achieve the following:

1. Harmonisation of training programmes in paediatric rheumatology between different European countries.
2. Establish clearly defined standards of knowledge and skills required to practice paediatric rheumatology at the tertiary level.
3. Foster development of a European network of competent tertiary care centres for paediatric rheumatology.
4. Improved care of children within Europe with chronic as well as acute rheumatic disorders.
5. Enhanced European contribution to international scientific progress in the field of paediatric rheumatology.

SYLLABUS

1. Knowledge

1.A Knowledge of Paediatric Rheumatology

- i Gain a thorough theoretical knowledge of the rheumatic diseases in childhood (listed in appendix A) including knowledge of epidemiology, aetiology, pathogenesis, pathology, differential diagnosis, clinical features, outcome measures and treatment.
- ii Become familiar with rheumatic diseases through the age spectrum.
- iii Understand the approach to rheumatological emergencies in children including acute arthritis, acute severe connective tissue diseases such as SLE, vasculitis and dermatomyositis, and paediatric emergencies presenting with musculoskeletal features such as non-accidental injury, neuroblastoma and leukaemia.
- iv Understand inter-relation of rheumatic diseases with other body systems, with particular emphasis on developmental stage and growth.

1.B Investigations

- i Understand haematological changes, acute phase reactants and biochemical changes that may accompany rheumatic diseases in children
- ii Understand genetic and immunological basis of such diseases: methodology of investigations for autoimmunity.
- iii Use of tissue biopsy of muscle, skin, synovium and kidney. Interpretation of histological abnormalities in children with rheumatic diseases.
- iv Understand place of radiological investigations including ultrasound, nuclear medicine scans, bone density, CT and MRI scans (with and without contrast) in the diagnosis of rheumatic disease in children.
- v Understand the use of investigations for following the progress of disease and for assessing the extent of damage to target organs, individual joints or other structures in the locomotor system and other systems affected by rheumatic disease.
- vi Understand the role of electromyography and nerve conduction studies in children with rheumatic disease.

1.C Pharmacology

- i Gain a thorough knowledge of non-steroidal anti-inflammatory drugs, slow-acting anti-rheumatic drugs, cytotoxic drugs, immunosuppressive drugs, biologic agents, corticosteroids, analgesics, gastroprotective drugs, growth inducing drugs, and treatment of osteoporosis.
- ii Be aware of the range and potential consequences of unconventional remedies and therapies given to children with rheumatic disease.
- iii Understand the pharmacology of the range of drugs used for control of pain in children
- iv Be aware of the use and risks of sedation for painful procedures in children (eg Midazolam)
- v Understand the importance of multicentre clinical trials in advancing therapeutic knowledge about rheumatic diseases.

1.D. Multidisciplinary Approach to the Care of Children with Musculoskeletal Disorders

- i Be able to use team approach to rheumatic diseases: understand its advantages and limitations.
- ii Understand methods used by nurses, occupational and physiotherapists, hydrotherapists, psychologists, dieticians, play therapists and social workers in the rehabilitation of children with rheumatic diseases including chronic pain.
- iii Understand school, community and social consequences of these diseases.
- iv Understand legal aspects of paediatric rheumatic disease.
- v Understand the role of allied specialities in treatment of paediatric rheumatic disease. This will usually occur during the course of attendance at specialist combined outpatient clinics in conjunction with orthopaedic surgeons, ophthalmologists, endocrinologists, child psychiatrist etc.
- vi Work with adult rheumatologists to provide transitional care, and understand differences and similarities between adult, adolescent and child.

1.E Medical Management

- i Gain management skills necessary for initiation and expansion of a paediatric rheumatology service.
- ii Experience different approaches to day to day running of a paediatric rheumatology service.
- iii Demonstrate organisational ability and communication skills required to arrange clinical meetings including case conferences, clinical audit and risk assessment.
- iv Communicate with primary and community care professionals and adult services.

1.F Continuing Education

- i Use computer-based literature searches and current paediatric rheumatological and allied journals to keep abreast of new developments in this rapidly changing field of medicine.
- ii Interpret results and conclusions presented in clinical research papers.
- iii Demonstrate competence at oral presentation of case and research material.
- iv Initiate, develop, undertake, write up and re-evaluate clinical audit projects in paediatric rheumatology
- v Be able to present data in national and international specialty meetings
- vi Maintain an up to date training record/educational portfolio of learning events.

2 Skills

Clinical Skills

- i Obtain a rheumatological history from a child and parents or carer, taking into accounts the child's developmental stage and growth.
- ii Perform a caring yet meticulous clinical examination of a child with a suspected rheumatic or musculoskeletal disorder.
- iii Assess and quantify the physical function of a child with rheumatic disease
- iv Assess clinical features and function of all potential target organs: kidneys, lung, CNS, heart, blood vessels, eyes, skin, muscle, bone and joints.
- v Assess pain in children
- vi Communicate with children of all ages and their parents, placing emphasis on counselling skills, the explanation of the disease to the child and provision of

appropriate disease education.

- vii Communicate and emphasise with parents/care givers of affected children in the emergency situation: employ appropriate counselling skills.
- viii Communicate risks and benefits of drug treatment as well as prognosis to children and their parents.
- ix Assess family interactions and their impact on clinical symptoms and signs.

Technical Skills

- i Aspirate and inject the knee
- ii Have experience in the arthrocentesis of other joints including the hip and sub-talar joints under ultrasound or other radiographic screening control.
- iii Perform soft tissue injections of tendon sheaths
- iv Understand the value and limitation of synovial fluid examination, synovial tissue biopsy and other biopsies relevant to rheumatology.

3. Attitudes

3.A Leadership

- i The trainee should demonstrate qualities of leadership and sensitivity to the team approach in the practice of medicine

3.B Communication

- i Effective and appropriate approach to parents, colleagues, GP and community healthcare staff, research and laboratory staff and manager.

3.C Education

- i Commitment to continuing self-education.
- ii Ability to teach paediatric rheumatology to doctors in training and professionals allied to medicine.
- iii Ability to teach paediatric rheumatology to medical students.

3.D Support

- i Supportive and sympathetic approach to handling families which can be maintained under difficult circumstances.

- ii Understanding a positive approach to the supervision of junior medical staff.
- iii Recognition of and coping with stress in self and others.

4. Academic/Research

- i Supportive of / active in research.
- ii Collaborative attitude to local and national colleagues.

5. Managerial

- i Interest in the overall organisation of departmental activities.
- ii Understanding approach to local management structure
- iii Constructive attitude to the process of decision making.
- iv Acceptance of shared responsibility for use of resources.
- v Ability to respond effectively to clinical complaints.
- vi Knowledge of issues covering ethics and consent for clinical trials.

6. Ethical Issues

- i Understanding the ethics of research in children.
- ii Understanding the process of informed consent.
- iii Knowledge of issues covering ethics and consent for clinical trials.

Key reference database

APPENDIX A

RHEUMATIC DISEASES OF CHILDHOOD

Inflammatory Rheumatic Diseases of Childhood

Juvenile Arthritis

- Juvenile Idiopathic Arthritis
- Arthritis associated with infection
 - Septic arthritis, osteomyelitis
 - Reactive arthritis
 - Acute rheumatic fever
 - Post-enteric / GU infection
 - Irritable hip / transient synovitis
- Arthritis associated with IBD

Connective Tissue Disorders

- Systemic Lupus Erythematosus
- Juvenile Dermatomyositis
- Scleroderma
 - Systemic sclerosis
 - Localised scleroderma
 - Eosinophilic fasciitis
- MCTD / Overlap Syndromes
- Primary Vasculitis
 - Polyarteritis Nodosa
 - Kawasaki disease
 - Microscopic Polyarteritis Nodosa
 - Henoch-Schonlein purpura
 - Hypersensitivity vasculitis
 - Allergic granulomatosis
 - Wegener's granulomatosis
 - Takayasu's arteritis
 - Other

Immunodeficiencies associated with Arthritis and CTD

- Complement Component Deficiencies
- Antibody Deficiency Syndromes
- Cell-mediated Deficiencies

Non-inflammatory Disorders

Idiopathic Pain Syndromes

- Reflex sympathetic dystrophy and localised pain
- Growing pains
- Fibromyalgia and diffuse pain
- Acute Transient Osteoporosis
- Erythromelalgia

Overuse Syndromes

- Chondromalacia Patellae
- Plica Syndromes
- Stress Fractures
- Shin Splints
- Tennis Elbow, Tenosynovitis

Trauma associated syndromes

- Slipped Upper Femoral Epiphysis
- Osteochondritis Dissecans
- Traumatic Arthritis, Non-accidental Trauma
- Congenital Indifference to Pain
- Frostbite Arthropathy

Pain Syndromes affecting back, chest or neck

- Spondylitis and Spondylolisthesis
- Invertebral disc herniation
- Slipping rib
- Costochondritis
- Torticollis
- Discitis
- Scheuermann's Disease

Skeletal Dysplasias

- Generalised
- Epiphyseal dysplasias
- Osteochondroses
 - Legg-Calve-Perthes Disease
 - Osgood Schlatter Disease
 - Thiemann's Disease, Kohler's Disease
 - Freiberg's Disease

Heritable Disorders of Connective Tissue

- Benign Hypermobility Syndromes
- Osteogenesis Imperfecta
- Ehlers-Danlos Syndromes
- Cutis Laxa
- Pseudoxanthoma Elasticum
- Marfan's Syndrome

Storage Diseases

- Mucopolysaccharidoses
- Mucopolidoses
- Sphingolipidoses

Metabolic Diseases

- Osteoporosis
- Rickets
- Scurvy
- Hypervitaminosis A
- Gout
- Ochronosis
- Kashin-Beck disease
- Mseleni disease
- Fluorosis
- Amyloidosis

Systemic Diseases with Musculoskeletal Manifestations

- Haemoglobinopathies
- Haemophilia and other bleeding diatheses
- Diabetes Mellitus and other endocrine disease
- Hyperlipoproteinemias
- Pseudohypoparathyroidism
- Secondary Hypertrophic Osteoarthropathy
- CF Arthritis
- Sarcoidosis
- Chromosomal disorders

Hyperostosis

- Infantile Cortical Hyperostosis (Caffey's Disease)
- Other

Neoplasia

- Leukaemia/lymphoma
- Neuroblastoma
- Primary Neoplasia of musculoskeletal system

Training Programme for the Tertiary Specialist in Paediatric Rheumatology

Structure of the Training Programme

In-line with all the other paediatric specialities, this training programme is structured in modules. Simultaneous training in different modules is possible. Completion of the training can consist of modules acquired in several different training centres which could be paediatric tertiary/academic centres, adult rheumatology departments or immunology departments. The trainee is to keep a “training record”. The number of centres contributing to the trainee’s programme however should not exceed a maximum of 5 within Europe. It is expected that a trainee will have experience in the whole of the syllabus as outline above. Due to international variations there are modules that are designated as “obligatory and those that are “desirable. We have also specified the minimum numbers of patients/procedures required for the whole training period rather than specified the minimum time required to be spent for each module.

It is clear that the evaluation process is key, both of the training centre and the trainees record. In each module relevant parts of the syllabus as outline in section 1 should be fulfilled in the training programme. The entire period of training to obtaining recognition as the European paediatric rheumatologist is a minimum of 2 years. It may be longer for those trainees that are unable to complete the syllabus within 1 or 2 centres. Due to variability of population and health care systems within Europe, paediatric rheumatology care is delivered not necessarily by a full time tertiary care specialist. In this event, a part time tertiary care paediatric rheumatologist should fulfil all the obligatory modules as outlined.

Obligatory Modules

1. *Juvenile Idiopathic Arthritis*

In patient and out patient care of patients with juvenile idiopathic arthritis. The trainee should acquire expertise in the knowledge of aetiology, clinical features, complications and treatment of children with chronic arthritis, as well as the impact of arthritis on growth and development.

The maximum number of patients to be seen during the training period is:

- Full clinical assessment of 50 new patients spread across all JIA disease groups
- 200 patients in continuous follow up care spread across all JIA disease groups
- some patients should be followed for at least one year (total follow up patients)

2. *Inflammatory Connective Tissue Diseases*

In patient and out patient care of the multisystem inflammatory connective tissue disorders (including SLE, juvenile dermatomyositis, juvenile scleroderma and paediatric vasculitis).

The trainee should have particular knowledge of the presentation of those diseases which often mimic chronic arthritis. The trainee needs to understand working with other specialists in paediatrics such as nephrology, dermatology, ophthalmology, and orthopaedic surgeons, as well as with adult rheumatologists.

The minimum number of patients to be seen during the training period is:

- 10 new patients spread across the following disease groups: SLE, scleroderma, dermatomyositis, primary vasculitis, PAN, WG, MPA
- 20 patients in continuous follow up care for at least 1 year

3. *Non-inflammatory Musculoskeletal Disorders*
Clinical diagnosis and management of non-inflammatory musculoskeletal disorders of childhood and adolescence including heritable disorders specified in the syllabus, Appendix A. A knowledge of the specific investigations for each disease and interpretation of the results are required for this module.
The minimum number of patients to be seen during the training period is:
 - 100 patients spread across all conditions listed in the syllabus under “non-inflammatory disorders”
 - 5 patients spread across the heritable disorders listed
4. *Emergencies in Childhood Presenting with Musculoskeletal Symptoms*
Differential diagnosis, investigation and practical inpatient and outpatient management of rheumatological emergencies in children. This includes diseases where the child is systemically unwell such as acute arthritis, SLE, dermatomyositis, vasculitis and other conditions presenting with rheumatological symptoms such as leukaemia, malignancies and non-accidental injuries.
The minimum number of patients to be seen during the training period is:
 - 20 patients from the above list
5. *Practical skills in Paediatric Rheumatology*
Joint aspiration and injection (see Syllabus: Section 2). Minimum to be performed: 50, to include experience with aspiration and injection of subtalar, ankle, knee, hip, small joints of fingers, wrist, elbow, shoulder and TMJ.
6. *Interpretation of Laboratory Data*
The trainee should be able to understand and interpret immunology tests including autoantibodies, complement studies, immunoglobulin levels, and HLA data. Interpretation of imaging results of relevance to the musculoskeletal system in childhood is required. The trainees should also understand the histopathological abnormalities of synovium, muscle, bone and skin and kidney.
7. *Rehabilitation skills for Juvenile Idiopathic Arthritis*
The trainee should understand the necessity for team working and the roles of the individual team members. Knowledge of clinical and functional assessment in children is necessary as is rehabilitation issues regarding the placement of the child in their family, home, school and community.
8. *The Pharmacology of drugs used for children with rheumatic disease*
The trainee needs to have a thorough understanding of all drugs used in the treatment of children with rheumatic disease including disease modifying agents, cytotoxic drugs and new and experimental approaches. The trainee also needs to have a good understanding of drugs used in adult rheumatology as these often impact on the treatment of rheumatic diseases in children.
9. *Pain management*
The trainee should have an appreciation of chronic and psychogenic pain as well as the management using a multi-disciplinary team approach. This module can include psychological and pain clinics where available.
10. *Teaching experience*
The trainee will learn to structure, prepare and present lectures to audiences within the hospital, as well as national/international meetings. The trainee will also have experience in

bedside and small-group teaching of junior doctors, medical students and professions allied to medicine, as well as parent and patient education.

11. *Research experience*

The trainee should have experience in extracting and synthesising information from published literature, carrying out audit projects and learning to plan, conduct, evaluate, and publish research projects. Required minimum: one publication in a peer-reviewed journal and one oral or poster presentation at a national or international meeting.

12. *Adolescent and young adult care*

The trainee will have experience in working with adult rheumatologists to provide transitional care for patients with chronic paediatric rheumatic diseases. Awareness and management of diseases associated with adolescence are required.

13. *Training in adult rheumatology*

A period of training in adult rheumatology is required in areas where the diseases are present in adulthood as well as in childhood eg, spondyloarthropathies, SLE. Attendances in adult specialist clinics are needed to increase the number of patients seen and to develop specialist skills.

14. *Ethical issues*

Understanding the ethics of research in children and experience in application to local ethics committees for clinical trials. The trainee should understand and carry out the process of informed consent for clinical research.

Desirable or Optional Modules

1. *Paediatric Intensive Care*

Critically ill children with paediatric rheumatic diseases including the multisystem diseases, often require periods of intensive therapy and care. Skills and knowledge gained in conjunction with other specialities as well as paediatric intensive care is desirable.

2. *Managerial skills*

This is a desirable skill which varies between countries. Interest and experience in the overall organisation of departmental activities, management structures as well as a constructive attitude to the process of decision making are desirable.

3. *Academic/Research*

The trainee will initiate in discussion with mentors, on research projects leading to a higher degree. This could be in an adult centre or unit carrying out basic science research.

4. *Practical skills*

The trainee may further develop skills in injection of joints under U/S or MR screening in skin or muscle biopsy according to the geographical area of training and the needs of the local health service.

Requirements for Entry into Specialist Training in Paediatric Rheumatology

These are general guidelines, taking into account regional differences in health service provision and population figures over Europe.

For a full time tertiary paediatric rheumatologist:

1. Common trunk of training in paediatrics

OR

2. Common trunk of training in internal medicine and in adult rheumatology. Essential modules from the paediatric common trunk will be added to the paediatric rheumatology modules. Guidelines on these general paediatric modules will be defined between EBP and EBR.