

involvement of the innate immune system in the homeostatic response either to the conventional programmed death of multinucleated myofibers and to the parallel occurrence of "non-canonical" cell death and survival programs, including necrosis and autophagy. Recruited phagocytes are responsible of the clearance of damaged myofibers and of dying muscle stem/progenitor cells, stromal cells and leukocytes. Muscle macrophages in particular are endowed with remarkable plasticity throughout regeneration and healing, switching from activated cells that generate inflammatory cytokines to reparative assets, that play a non redundant role during the resolution phases of the damage and regulate the termination of the inflammatory responses. This dynamic transition between is increasingly felt to be the key to muscle homeostasis. Conversely defects in the process favour maladaptive remodeling with deposition of collagen and fat accumulation and in predisposed individuals autoimmunity leading to inflammatory idiopathic myopathies. A specialized population of regulatory T (Treg) cells, which control the inflammatory response by promoting the M1-to-M2 switch, and the activation of the muscle stem cells, satellite cells is receiving increasing attention for their central role in tissue homeostasis. Thus, the immunological perception of muscle cell death and regeneration – in turn influenced by environmental cues, including mitophagy and alteration of the redox balance - determines whether these events foster successful tissue healing or persisting inflammatory myopathies. The insights that are progressively become available on this original scenario hold promises to develop new approaches for disease treatment. Thus, immunologic perception of death and regeneration of muscle cells determine whether these events promote healing of tissues or persistent inflammatory myopathies. The insights that are becoming increasingly available on this original scenario hold promise for the development of new approaches to the treatment of persistent human muscle disease.

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To be and to become: transition from paediatric to adult care

SP0064 TO BE AND TO BECOME: REFLECTIONS ON MY TRANSITION

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The importance of successfully transitioning pediatric patients to adult care is increasingly recognized across a wide range of health care providers. However, there are still many challenges occurring during the transition phase. This presentation will contribute to these challenges by sharing the journey of a young person with arthritis on the transition to adult care.

As a young patient with arthritis, I made the journey from pediatric care to adult care a couple of years ago. I am diagnosed with arthritis since I was 14 years old. In this presentation, I will show the experiences of my own transition. Furthermore, as the chair of Youth-R-Well.com, an organization for young people with RMDs in the Netherlands, I will share some of the main points around transition I learned from other young patients. For every person, the transition to adult care is experienced different. Therefore, I will try to give some main answers from personal journeys on the questions: How is the transition experienced by a young patient? What are the current challenges faced by a young patient during the transition? What should be the role of the parents during the transition? What are best practices for the transition to adult care?

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SP0065 ARE WE ASKING THE RIGHT QUESTIONS IN TRANSITION RESEARCH?

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Already in 1991 Robert Blum pointed to the diverse set of issues of which the clinicians need to be cognisant to successfully care for youth with chronic illness. Since then, the special health care needs of adolescents and young adults with chronic diseases, including rheumatic diseases, have been on the agenda. Despite efforts to develop holistic services and programmes for youth, there are still inconsistencies in service delivery and practice standards. This revealed a survey among paediatric rheumatologists from 115 centres in 22 European countries in 2016. A minority of European paediatric rheumatology centres have a written transition policy, follow a standardised, structured approach in transitioning patients and measure the success of their interventions with evaluated instruments. To overcome these deficits and existing practice variation, key elements of transitional care, frameworks and pathways to implement and assess transition programmes have been recommended by EULAR and PRES. However, as long as we don't have robust evidence upon best practice for transition, on the best metrics for measuring "success" and "outcome" of transitional care services and on the impact of interventions on the young people with rheumatic diseases will the service planning and delivery for transition aged youth remain suboptimal and result in adverse long-term outcomes.

The literature about transitional care is exponentially increasing each year and comprises among others assessments of experience of care and clinical outcomes, evaluations of different services and processes of care. What we have learned so far from transition research in the field of rheumatology, which research priorities are currently set on the agenda by health care providers and whether they meet those of young people will be in the focus of this lecture.

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SP0066 IMPLEMENTATION OF A BRIEF TRANSITION PROGRAMME FOR ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS

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Background: It is well described that adolescents and parents find transition between the children's and adult ward challenging (1–2) because they feel inadequate prepared, and find communication and cultural differences between child and adult care challenging. Thus, transitional care programmes becomes essential for a successful process (3).

Objectives: We aimed to develop a brief transition programme for adolescents with juvenile idiopathic arthritis (JIA), suitable for daily clinical practice in the children's and adult ward of rheumatology at Aarhus University Hospital, Denmark. **Methods:** The development was based upon studies of transitional care programmes and qualitative studies of the patient, parent, and health professionals perspective in the transition process. Needs in the transition process from the perspective of both adolescents and parents were further investigated through semi-structured interviews. We used studies by Janet McDonagh and colleagues (3) as a theoretical framework for the programme development.

Results: The programme focuses on the final part of the transition process by including the adolescent from the children's ward at the age of 14. It runs for two years in the children's ward and continues the first year in the adult ward. The programme focuses on preparing the adolescent and parents for transition by enhancing the adolescent's knowledge and skills in coping with JIA. The programme further focuses on the relation between the adolescents and parents by bringing attention to the need for a gradually separation, and to placing more self-dependence on the adolescents. A guideline, describing the programme, containing concrete instructions to health professionals has been developed. The programme was primarily initiated by the adult ward, but nurses and physicians in both wards have been involved throughout the process.

The programme consists of the following elements;

- Assigned contact persons.
- Information leaflets about transitional care, transfer to adult care and differences between the children's and adult ward, i.e. in ways of working and treatment procedures.
- Independent consultations with health professionals.
- Materials for educational sessions.
- Educational sessions dealing with JIA and treatment, dialogue on adherence and challenges in adolescence.
- Arrangements of visits to the adult ward before transfer.

Conclusions: Our experiences with the programme in practise are generally positive. However, we have experienced that successful implementation calls for good collaboration and continuous involvement of the health professionals involved in the programme on a daily basis. Hence, ongoing meetings and communication have been essential to promote collaboration between the children's and adult ward.

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Heterogeneity in JIA

SP0067 CYTOKINES IN JUVENILE IDIOPATHIC ARTHRITIS

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The importance of cytokines in the pathogenesis of inflammatory diseases is highlighted by the success of therapeutic approaches directed against cytokines and cytokine receptors. Cytokines are characterized by their redundancy and pleiotropy: multiple cytokines can target the same receptor, while on the other hand a single cytokine can have multiple, even contradictory immunological effects.

Linking a cytokine/protein biomarker signature with clinical outcome may help to identify and classify patient cohorts. Thus "intelligent" cytokine signatures can be used as biomarkers in human inflammatory diseases. There are however various risks associated with this approach; often it is impossible to obtain material from the site of inflammation and there are various often not well-known technical aspects crucial to obtain reliable and usable results. Although standardization has been prominent in day to day clinical practice, standardization of sample collection and laboratory assessments remains suboptimal. Inconsistency in sample collection can affect the results of biological assays and thus several characteristics require thorough evaluation and standardization. This standardization is not limited to assay validity and reproducibility but also pre-analytical treatment and appropriate specimen types.

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SP0068 CLINICAL INSIGHTS INTO JIA HETEROGENEITY

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Several epidemiologic surveys have documented a remarkable, yet unexplained, disparity in the prevalence of juvenile idiopathic arthritis (JIA) subtypes among different geographic areas or ethnic groups. Moreover, the therapeutic approach to JIA is not standardized and the availability of the novel and costly biologic medications is not uniform throughout the world. This disparity may have significant impact on disease outcome. The multinational study of the Epidemiology, treatment and Outcome of Childhood Arthritis (EPOCA study) is aimed to obtain information on the variability of JIA phenotypes in different geographic areas, the therapeutic approaches of pediatric rheumatologists practicing in diverse countries, and the disease status and outcome of children with JIA currently followed worldwide. Participation in the study was proposed to all pediatric rheumatology centers that are part of the Pediatric Rheumatology International Trials Organization (PRINTO), and to several centers in the US and Canada. Each center was asked to enroll 100 consecutive JIA patients or all consecutive patients seen within 6 months. Each patient received a retrospective and cross-sectional assessment. Parent- and child-reported outcomes were recorded through the administration of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR). Participating countries were grouped into 6 geographic areas. Patients were then grouped according to their country's gross domestic product per capita (GDP) and the total expenditure on health per capita (HE) (source www.who.org). Currently, 8,325 patients from 44 countries have been entered in the web database. Comparison of main epidemiology, treatment, and outcome features across the different geographic areas was performed. Patients living in countries with GDP or HE below the median had lower frequency of remission, higher median cJADAS, higher frequency of damage, and were less frequently prescribed biologic DMARDs. These results were confirmed when analyses were conducted only in oligoarthritis or polyarthritis patients. These results provide further evidence of the wide difference of JIA characteristics across geographic areas in terms of age at disease onset, subtype prevalence, and frequency of anterior uveitis. Overall, patients living in non-Western countries had higher levels of disease activity and cumulative damage than patients followed in North America and Western Europe. This disparity in disease outcomes may be partially due to differences in the availability or affordability of biologics, as confirmed by the evidence of worst outcomes in countries with lower GDP or HE.

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EULAR - EMA session

SP0069 REGISTRIES IN MUSCULOSKELETAL DISEASES AND THEIR REGULATORY USE

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Patient registries collect information about individuals sharing health-related characteristics, for example, a particular disorder, a treatment or a procedure. While randomised controlled trials typically provide the primary evidence supporting marketing authorisations for new medicines, the patients studied may not be fully representative of everyone ultimately receiving the medicine and the trials may provide limited information about the natural history of the disorder. Information collected in patient registries is potentially of value for filling these evidence gaps in certain situations and for providing post-marketing safety and effectiveness information. Multiple stakeholders stand to benefit from using registry information in this way including patients, healthcare providers, policy makers, manufacturers and healthcare regulators.

In 2014, the EMA commenced a Registry Initiative aiming to optimise the use of registries in supporting medicines authorisations. Establishing a strategy of early engagement between marketing authorisation applicants and registry holders and a task force to support activities, a pilot phase was undertaken aiming to understand the barriers and enablers in using registries to support marketing

authorisation applications and to inform the development of recommendations to optimise their use.

On 28 October 2016 the Agency organised Patient Registries Workshop to collect and discuss the information about experience from different patient registries in various therapeutic areas. The topics included:

- Benefits of registries for regulators
- Benefits of registries for HTA and payers
- Benefits for industry
- Benefits for clinicians and researchers
- Benefits for patients
- Challenges in collaboration between registries
- Technical challenges
- Governance
- Sustainability

Conclusions of the pilot and the workshop have been utilised in the following activities including workshops to support registries in individual diseases.

There are multiple advanced registries in RA and JIA. Utilisation of outcomes of these and other existing or newly planned registries in other musculoskeletal diseases for regulatory purposes current environment offers new opportunities that require further analyses and collaboration.

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SP0070 NEWS FROM OMERACT – IMAGING AND MORE

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Objective In rheumatoid arthritis (RA), MRI provides earlier detection of structural damage than radiography (X-ray) and more sensitive detection of intra-articular inflammation than clinical examination. This analysis was designed to evaluate the ability of early MRI findings to predict subsequent structural damage by X-ray. **Methods** Pooled data from four randomised controlled trials (RCTs) involving 1022 RA hands and wrists in early and established RA were analysed. X-rays were scored using van der Heijde-modified or Genant-modified Sharp methods. MRIs were scored using Outcome Measures in Rheumatology (OMERACT) RA MRI Score (RAMRIS). Data were analysed at the patient level using multivariable logistic regression and receiver operating characteristic curve analyses.

Results Progression of MRI erosion scores at Weeks 12 and 24 predicted progression of X-ray erosions at Weeks 24 and 52, with areas under the curve (AUCs) of 0.64 and 0.74, respectively. 12-week and 24-week changes in MRI osteitis scores were similarly predictive of 24- week and 52-week X-ray erosion progressions; pooled AUCs were 0.78 and 0.77, respectively. MRI changes in synovitis at Weeks 12 and 24 also predicted progression of X-ray joint damage (erosion and joint-spacenarrowing) at Weeks 24 and 52 (AUCs=0.72 and 0.65, respectively).

Conclusions Early changes in joint damage and inflammation detected with MRI predict changes in joint damage evident on subsequent X-rays. These findings support the use of MRI as a valid method for monitoring structural damage in short-duration RCTs.

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Barrier free employment for young people with RMDs

SP0071 YOUNG PATIENTS: READY, BRILLIANT AND ABLE TO WORK!

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In May 2016, European Young Patients Group, an initiative representing young patients from the European Patients' Forum (EPF) and the European Multiple Sclerosis Platform (EMSP), organised a workshop in the framework of the European Youth Event (EYE) 2016 in Strasbourg that corresponded with one of the five main programme themes titled, Exclusion or Access: Crackdown on Youth Unemployment.

The physical and emotional symptoms of chronic conditions, together with social stigma and attitude, create significant barriers to young patients in the job market. With appropriate support, they, like all enthusiastic young people, can be assets for employers. Through interactive discussion, creative expression, education and open dialogue, the workshop aimed to challenge expectations and inaccurate perceptions about the abilities of young people with chronic conditions, tackle societal beliefs and stereotypes of individuals with chronic conditions, stimulate discussion to explore concrete solutions and develop practical actions for young people and their allies accessing employment and steer change to ensure young patients benefit from equal opportunities and treatment at work. By addressing these specific objectives, the workshop was to ultimately raise awareness of the extra burdens faced by young people with chronic conditions transitioning from education to employment, as well as bringing public attention to the stigma and discrimination that exists at both the recruitment stage and in relation to employees disclosing their health conditions. It also was to compliment and