SP0036 FREE FATTY ACIDS: GOOD OR BAD IN RHEUMATOLOGY?

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Free fatty acids (FFA's) are grouped based on the length of their carbon chains into short chain fatty acids (SCFAs), medium chain fatty acids (MCFAs) and long chain fatty acids (LCFAs). The most FFAs are released after breakdown of triglycerides in adipose tissue and the liver. However, SCFAs including acetate, propionate and butyrate are derived from the fermentation of fibres in the gut. In this presentation, the good or the bad properties of FFA's to control or aggravate inflammation in general will be discussed. With special focus on rheumatic disorders, such as rheumatoid arthritis and gout. In addition, the synergy of LCFAs with damage associated molecular patterns (DAMPs) will be addressed. Finally, the therapeutic value of SCFAs will be discussed in rheumatic disorders.

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Inclusive school environment for young people with RMDs

SP0037 INCLUSION OF ILL CHILDREN INTO THEIR HOME SCHOOL BY REAL TIME EDUCATION

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The right to education, even when ill

It seems self-evident. Even when you are ill for a long time, you preserve the right to learn and keep your place in the social environment of your class group.

For 25 years now the right to education has been established as a right of every child, as formulated in the Convention on the Rights of the Child. Since 2006 Bednet makes sure that this fundamental right is fulfilled. Bednet takes care that children and youngsters who are absent for a shorter or longer period because of physical or mental illness, surgery or pregnancy, can continue attending the lessons – from their home and with their own class group. In the educational law it is called: synchronous internet education (SIE).

But it is only since 1 September 2015 that synchronous internet education (SIE) is structurally embedded in the educational system of the Flemish Community. This results in the right to SIE for every child with a chronic or long term illness.

Along with lessons, and all the rest

Bednet takes care that children and youngsters who are absent for a shorter or longer period because of physical or mental illness, surgery or pregnancy, can continue attending the lessons – from their home and with their own class group.

It is available for pre-school children from the age of 5, pupils of primary and secondary schools. The equipment and the counselling is free for schools and families, and this throughout the period in which the child needs it.

Bednet aims at limiting arrears in learning by providing a set of tailor-made lessons. This way 9 children out of 10 succeed in passing on to the next class despite their absence from school. Moreover Bednet makes an opening in the isolation of the child by enabling regular contacts with peers. The illness recedes to the background and the child is temporarily back with friends 'in his or her class group'. The non-profit organisation always collaborates with the parents, the school and other partners, such as the hospital schools and volunteers.

Bednet in practice: Bednet creates a live connexion between the pupil with an illness and his or her class group. The pupils and the teacher see the youngster on the flat screen at the back of the classroom. The child at home can direct a camera, enabling him or her to attend the lesson and/or talk to peers. Bednet uses a system that is easy to use. The pupil participates actively in the lesson, answers questions, can send and receive documents and take part in group work. Just as if the pupil were really sitting in the classroom.

Bednet operates with regional consultants in the different provinces. They do the follow-up of the children and confer with parents, hospital and school. They plan everything and take care of the concrete organisation. A technical helpdesk supports children and school throughout the project.

Bednet in numbers:

- In the first full school year during which Bednet was active (2007–2008), 37 children were supported.
- Since the start more than 1,900 children with a long time or chronic illness have used Bednet in 1,250 Flemish schools with synchronous internet education.

- The children and youngsters live in all parts of Flanders and Brussels. Two out of three Bednet users attend secondary school.
- Cancer remains the most common pathology with 21% of all users. Also patients with rheumatology belong to the target group of Bednet.

The future: Under the authority of the Flemish Government Bednet faces the big challenge of guaranteeing the right to SIE for each and every child with a long term illness. It is gradually being extended to cover all children with a long-term absence from school in the whole of Flanders. It is estimated that numbers could grow to 1.000 children in 2018.

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SP0038 RAISING AWARENESS OF INVISIBLE ILLNESSES IN SCHOOLS AND EDUCATION

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Introduction

RAiSE is a user-led research project inspired by the negative experiences that young people face while studying and living with an invisible illness. Many young people who live with chronic illnesses look no different to their healthy peers. The invisible nature of some illnesses can often lead to an invisible struggle, leading to misunderstandings, particularly in the case of young people. It can be a huge burden on the chronically ill to make the invisible, visible to others.

Objective: The main objective of RAiSE is to improve the standard of care given to young people with invisible illnesses in school and college and to create a resource to teach education professionals a series of strategies and techniques to support their students. RAiSE will also offer support to young people with invisible illnesses and aim to empower them to take control of their own health.

Methods: A young patient of Alder Hey NHS Children's Foundation Trust decided to raise awareness of living with an invisible illness. A network of young people, parents, education and health professionals was created and a series of workshop and focus groups allowed each stakeholder to share their experiences and expertise as they inspired and advised the production of the RAiSE information pack. It is important that young people are able to shape research based on their lived experiences. Several international charities and organisations have offered support and knowledge in advising the process.

Results: At early workshop meetings, young people with invisible illnesses and their parents were able to offer personal accounts and experiences which highlighted that the most common themes were problems with communication and trust, as well as difficulty in understanding the erratic nature of many chronic illnesses. From this research, a draft information pack was written by the RAiSE committee, which was later presented to young people, parents, health and education professionals and charity representatives. All stakeholders were able to offer their expertise from their respective fields. Feedback was overwhelmingly positive and any adjustments are to be made in the coming weeks. The final pack will be completed and ready for distribution by the end of summer 2018.

Conclusion: The project has been a successful example of young patient led research and highlights the importance of self-management in young people living with invisible chronic illnesses. The collaboration between young people, parents, and education and health professionals has highlighted the necessity for cooperation between all stakeholders for the benefit of the young person.

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SP0039 I GRADUATED! EDUCATION FOR CHILDREN AND ADOLESCENTS WITH RMDs

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Communication is the key to success in practically every situation. Without communicating to your counterpart, how should they understand your own situation?

When it comes to studying with a chronic illness we need to know how the illness affects our ability. We need to communicate what we are able to do and where we need support. When I started my Master Degree I have been honest from the very beginning. I never kept my rheumatic disease and the disability that comes with it a secret. Being open from the very beginning gives yourself and your university, school or even workspace the opportunity to adapt to your abilities. Hiding your disability will make it hard for yourself to keep up with your class. Your fellow students and teachers not knowing what your limitations are will most certainly lead to misunderstandings.

Many pupils and students do not know that there are laws and regulations that could help them to get through school easier. For example you are allowed to have longer writing times in exams, or use your computer for typing texts instead of having to write by hand. This helps to prevent pain in your joints. There are

even more ways in which your university or school can help you to get through your day than you would think of in the first place. Without asking for help, you will never find out what is actually possible. Through communicating with a disability-spokesperson you will most likely get even greater support.

In my lecture I will talk about my own story and how I managed to finish my Bachelor Degree whilst falling chronically ill with Adult Onset Still's Disease. I will give examples on how to handle a life with chronic illness. There will be some tips on what to do when your counterpart is not as understanding as he or she should be. I will explain what I do to get me through lectures and exams.

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SP0040 PARENTS SUPPORT FOR CHILDREN WITH RMDS IN EDUCATION

M. Kopic. Society for Children with Immune Disease, Komenda, Slovenia

My presentation will contain situation in schools all across the Europe (at least 13 countries/results from a survey and info which I get from our Associations, members of ENCA).

It is serious situation. First I will present the problems, we, parents, are struggling with every day. I will also prepare and present possible solutions. One country is extra good in solutions and they really take good care for children with autoimmune conditions and we can learn from them. I will also present a concrete good solution.

Solutions should be used as a prepared document for all the countries. That is a goal of ENCA.

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WIN and HOT session

SP0041 WIN SESSION: WHAT IS NEW IN THE TREATMENT OF MYOSITIS?

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Much progress has been made over the last decade in the understanding of the inflammatory myopathies. It is heartening to see some of these developments now in clinical practice which is hopefully increasing the quality of care for myositis patients. This talk will summary the new upcoming treatments in myositis. However, treatment of a rare disease not only involves administering pharmacotherapeutic agents, but recognising when to treat and which poor prognostic groups required intensification. Antibody testing of the spectrum of newly identified myositis serology now allows for better stratification of patients and assists the physician with treatment, monitoring and prognosis. New EULAR/ACR criteria are available for classification to assist inclusion into clinical trials, as well as agreed definitions for minimal, moderate and major response. A better understanding of the pathogenesis has now led to randomised controlled trials now being conducted in the inflammatory myopathies, including targeting the innate immune pathway that will hopefully lead to a licensed treatment for this difficult orphan disease.

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SP0042 RECENT ADVANCES IN THE TREATMENT OF SYSTEMIC SCLEROSIS

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Few rheumatological diseases have seen as many false dawns as systemic sclerosis (SSc) and many drugs once hailed as promising have fallen by the wayside. Clinical trials have been plagued by poor accrual, difficulties with definitions of endpoints, clinical heterogeneity of disease manifestations and variability of disease course, resulting in inconclusive or negative trial results. Clinicians standing in the shadows of no man's land could be forgiven for not seeing the sparks of light around them. Yet our grasp of the pathological pathways operative in SSc,

consensus on endpoints and international collaboration have paved the way for clinical trials with novel antibiotic and immunomodulatory drugs (e.g. rociguat, JAK-STATi) that could change the way we treat SSc. For now we will have to stick to old friends such as methotrexate, MMF and cyclophosphamide in early diffuse cutaneous SSc, even though their clinical benefit is modest at best as shown in the ESOS study and expressed in recent guidelines.¹⁻³ Rituximab is increasingly being used based on observational studies in SSc and its proven potency in rheumatoid arthritis, but requires more robust data. Tocilizumab has shown unexpected benefit on lung function in a phase 2 trial,⁴ which if confirmed with phase 3 trial could transform the way we manage SSc-ILD. As of yet, the only proven disease modifying therapy in early progressive SSc is autologous hematopoietic stem cell transplantation, shown to be effective in two prospective, controlled randomised clinical trials (ASTIS and SCOT, conducted in Europe and North America respectively).^{5,6} Only a small group of patients qualify for this however and even fewer have access to centres with the necessary expertise. SSc continues to constitute an area of unmet need, yet progress is being made, albeit slow.

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Can we halt progression of structural damage in axial SpA?

SP0043 HOW TO CAPTURE CLINICALLY RELEVANT STRUCTURAL PROGRESSION IN AXIAL SPA

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Structural damage in axial SpA usually refers to the sacro-iliac (SI) joints or the spine. The classic order of the progress of structural damage is in the SI joints, followed by the spine. Consequently, in early disease assessment of structural damage should be focused on the SI joints and in established disease (i.e. in patients with radiographic sacroillitis) evaluation of the spine becomes more useful.

The most striking abnormality representing structural damage in axial SpA is bone formation, although in early phases bone destruction can also be seen. Typically, structural damage is assessed on radiographs.

For radiographs there are two frequently used scoring methods: grading of the SI joints according to the modified New York (mNY) criteria and assessment of the spine by the modified Stoke Ankylosing Spondylitis Score (mSASSS). The mNY grades range from 0–4 per SI joint, 0–8 in total. Although it is well known that reliability of mNY grading is poor, this continuous grading has recently been successfully used as an outcome measure. The mSASSS is mainly based on bone formation in the anterior vertebral corners in the cervical and lumbar spine (range 0–72). It is a reliable measure but the progression observed by mSASSS is rather modest, resulting in a minimum follow-up of two years.

Imaging of structural damage by MRI is another option. Due to the imaging of the whole spine and the three-dimensional technique this seems an attractive alternative. However, especially bone formation is very hard to assess. Fatty deposition is a typical MRI abnormality, which can be seen as an intermediate step between inflammation visible on MRI and bone formation on radiographs. However, this finding is insufficiently validated to be able to consider it as a true surrogate for structural damage.

Finally, a CT scan is a method having the advantages of MRI (whole spine, tomographic technique) but also the best capabilities of bone imaging. The big disadvantage of CT scan is the radiation dose. Recently, it became possible to make images with good image quality but acceptable radiation, the so-called low-dose CT. A validated scoring system for CT exists: the CT scoring system (CTSS). Only bone proliferation is assessed in this method. In a direct comparison with mSASSS more progression was observed over a 2 year period. This was mainly due to the progression observed in the thoracic spine.

Only structural damage assessed by the mSASSS has shown a clear relationship with outcomes that are important for patients such as function and quality of life. No data on MRI or CTSS exist. However, it is hard to describe what defines a clinically relevant progression. The interval to assess progression to assess a