prevalence of diabetes mellitus, however, appears to be similar to the general population. Smoking has been reported to predict RA *per se*, but reports on the prevalence of smoking in RA are contradictory. Several studies have reported decreased lipid levels in active RA with quantities inversely related to the acute phase reaction. Lipoprotein (a), was however increased and in patients with high levels related to inflammatory variables. Concerning the use of corticosteroids, epidemiological reports have failed to identify their use as a risk factor for CVD in RA. In a retrospective cohort study on 211 patients with early RA, followed-up after 19–21 years, we found the inflammatory activity at disease onset (ESR, haptoglobin), and during disease progression, to predict cardiovascular event. In contrast to a report on increased risk of death due to CVD following the use of methotrexate, we found DMARDs, and specifically antimalarials, to be protective. Vasculitis, overt or subclinical, has been suggested to be one cause of CVD in RA and in a recent report RA *per se* actually was shown to predict IHD independently. A population based study showing that the number of swollen joints could predict death from CVD further implicated a harmful impact of the inflammatory activity on the vascular system. The etiopathogenic basis for this harmful effect still has to be elucidated.

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Working in partnership – Thursday 14 June, 16.00-17.30/Forum Hall

SP0046 WHAT ARE THE NEEDS OF THE INDIVIDUAL – MANIFESTO FOR AND BY PEOPLE WITH ARTHRITIS/ RHEUMATISM IN EUROPE

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As people with arthritis/rheumatism we recognise that we have a unique role in pressing for the provision of adequate care, treatment and support for the more than 100 million people with arthritis/rheumatism throughout Europe.

With this goal in mind, in April 1999, several arthritis/rheumatism patient organisations met to discuss how they could work together to address their mutual concerns, challenges and aspirations. That gathering, and a number of subsequent committee and steering group meetings, have led to the development of the Manifesto for the Third Millennium, by people with arthritis and rheumatism in Europe.

Prior to this, patient groups in the field of arthritis/rheumatism had not had the opportunity to share these concerns and articulate them with one strong, united voice across Europe. There was an abundance of ideas but no resourced system to develop them and no platform from which they could be launched.

Whilst by no means an all-compassing document, the Manifesto is intended to provide a 'Call to Action' on those issues people with arthritis/rheumatism in Europe believe to be of the highest priority to them. As the document sets forth, they hope to establish a productive framework for collaboration between patient organisations, medical and health professions, policy makers, and others, throughout Europe: a framework that brings empowerment to people with arthritis/rheumatism and a commitment to best practice across Europe.

The Declaration is as follows:

As people with arthritis/rheumatism we declare that:

Since at least 103 million European citizens have arthritis/rheumatism, we comprise the largest part of the population living with long-term medical conditions. We share a great concern about the serious health, social and economic impacts of arthritis/rheumatism because it affects every aspect of life. The pain and disability have consequences for our families, friends, employers, government policy, and society generally. Despite this, many of us do not have the opportunity to get appropriate treatment and support. Arthritis is not prioritised in the European health agenda, and European governments do not have effective national strategies to engage effectively. This amounts to an infringement of the Universal Declaration of Human Rights. It is important to recognise and utilise the experience of those of us who have learned to self-manage our arthritis effectively. We believe that our experience and knowledge should be used as a resource for the benefit of others so that they too can enjoy a high degree of independence and a good quality of life.

To help us achieve our Manifesto for the Third Millennium we require the support of European policy makers, service providers and researchers to:

- Raise public awareness (of the scale and impact of arthritis/rheumatism. ...)
- Empower people with arthritis/rheumatism by funding user-led programmes (that draw on the skills of people with arthritis/rheumatism. ...)
- Involve people with arthritis/rheumatism in policy development (...)
- Develop and recognise national and international organisations of people with arthritis/rheumatism (...)
- Provide prompt and good quality health and community services (...)
- Ensure doctor and health professional awareness of arthritis/rheumatism (is focused on patterns of therapy, treatment and support that enhance our independence and autonomy as individuals with arthritis/rheumatism. ...)
- Involve people with arthritis/rheumatism in helping to determine relevant medical research priorities and budgets, (methodologies and the communication of findings, thus establishing a comprehensive knowledge base for the planning of services.)
- Expand research into the societal impacts of arthritis/rheumatism (by involving people with arthritis/rheumatism in all aspects. ...)
- Strengthen laws and regulations (...)
- Provide fully accessible education/training programmes (...)

The Manifesto is prepared by:

Arthritis and Rheumatism International (ARI) + Standing Committee of the European League Against Rheumatism

(EULAR) Social Leagues + International Organisation of Youth with Rheumatism (IOYR).

SP0047 ASSESSING THE NEEDS OF THE INDIVIDUAL

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The shift away from service driven to needs lead service delivery will be explored.

The needs of the individual during the phases of disease progress will compare perceived versus actual. Contribution of the multidisciplinary team at all stages will be highlighted.

The move to patient/individual self-efficacy and the effect on relationships with health professionals provide an arena for potential conflict. The health professionals perception of the individuals needs are often not compatible with the actual needs of the individual.

The results of an in depth interview, with a patient, will explore their needs and whether they have been met. (An interview audited tool will be used).

Financial constraints, shortage of health professionals, the political agenda, compliance of the individual and "patient power" will highlight the areas of unmet needs.

The needs of carers and service providers are often neglected at the expense of the "individual". The conflict of the carer and individual will also be addressed.

Does the individual know best?

REFERENCES

- 1 Arthritis Impact Measurement Scales (AIMS)
- 2 Health Assessment Questionnaire (HAQ)
- 3 SF – 36 Health Survey
- 4 The NHS and Community Care Act 1990

SP0049 RAISING PRIORITY FOR THE NEEDS OF THE INDIVIDUAL

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Musculoskeletal conditions (MSC) have an enormous and growing impact recognised by WHO Europe in "Health 21" yet national health care priorities in most European countries do not include them. The aim of the Bone and Joint Decade is to redress this imbalance by advocacy supported by evidence. To improve the outcome for the individual greater priority has to be given to the provision of existing proven interventions that meet the needs and wishes of the person with a MSC, and better interventions need to be developed through research. Education of public, people with MSC, health care providers, politicians and health professionals is fundamental to changing the negative perception of what can be achieved and in improving standards of care. Any campaign to meet these objectives needs to be supported by relevant data of the impact of MSC and evidence based solutions to reduce this. Key messages that highlight the issues, priorities and these solutions need to be developed for the decision-makers and any other relevant audiences. These messages should be conveyed by the powerful alliance of those with MSC and those who provide their care. The potent image of advocates must be used to attract media attention that is central to the strength of any campaign. Finally targets must be set

to measure the success of any campaign. The Bone and Joint Decade is identifying the burden of MSC with the WHO and developing evidence based strategies for prevention with the support of the EU. National and local campaigns are necessary that use this evidence to achieve change and fulfil the aim of the Decade, which is to improve the health-related quality of life for those with musculoskeletal conditions.

T-Cell activation and MHC – Thursday 14 June, 16.00-17.30/South Hall

SP0050 THE ROLE OF HLA IN RHEUMATOID ARTHRITIS: INDUCTION OF AGGRESSION OR FAILURE TO PROTECT?

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Genetic factors contribute both to the development and the course of Rheumatoid Arthritis (RA). The contribution of inherited genetic variability has been estimated 60%. Moreover, stochastic processes during the development of the T and B lymphocytes repertoire or so-called somatic genetic diversity may be responsible for an as yet unknown fraction of the remaining 40% of the factors contributing to the pathogenesis of RA.

Thus far, the only known inherited genetic factors are encoded by the HLA system. These factors contribute about 40% of the inherited genetic variability and also contribute to the somatic genetic diversity. The main contribution of the HLA system is conferred by the HLA class II region and HLA-DR genes are certainly involved but HLA-DQ genes also may have a contribution. Perhaps most importantly: certain HLA-DR genes may provide dominant protection. HLA genes not only contribute to the development but also the course and severity of RA. There is also evidence for dominant protection against the development of erosions. We observed that this effect may be relatively short-lasting and overruled by a very early start of treatment with DMARDs (Yard *et al.*, submitted for publication). These observations suggest that pharmacogenomics may offer possibilities for a tailor-made optimal treatment for individual RA patients. The standard hypothesis for an association of an HLA class II allele with an auto-immune disease is that auto-reactive T cells recognise certain self-epitopes that are exclusively or preferentially presented by that particular HLA class II allele. The Shared Epitope (SE) hypothesis (Gregersen *et al.* 1987) is a paradigm of this. More than 20 years of intensive research along these lines have however yielded little evidence for this concept. Therefore, we have developed an alternative hypothesis. In this hypothesis auto-reactive T cells do not play a role in the initiation but in the regulation of the disease process (Zanelli *et al.*, Rheumatology, in press). Our model is an extension of the one proposed by Thomas and Lipsky (Immunology Today 1996; 17: 559–560). It starts with activation of synoviocytes by a trauma or an infection. Usually this results in a local inflammation that resolves in a few days, but in the presence of one or more (yet to be identified) genetic factors (not HLA class II) an aberrant activation of synoviocytes results in a chronic inflammation. As proposed by Thomas and Lipsky chemo-attraction of dendritic