

Report on the
13th ASIF Council Meeting
Held at the Marriott Hotel Tianhe,
Guangzhou, China.
11-13 October, 2018



Wednesday, 10 October, 2018: Arrival of delegates

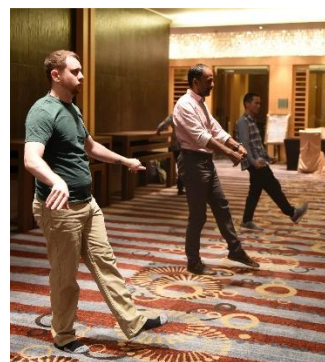
Delegates, observers and guests arrived by 'plane or train on 10 October and were met by volunteers from the Ankylosing Spondylitis Patient Association, China Health Promotion Foundation, who escorted them to the Marriott Hotel on Tianhe Road in Guangzhou.

In the evening a welcome reception was held. To allow everyone to get to know each other, some lively icebreaker games were held. These required everyone to get to know everyone else's name and how long they had been involved with their home Ankylosing Spondylitis ("AS") organization. The reception was followed by a buffet dinner in the hotel.



DAY 1 - Thursday, 11 October

For those who wished to participate, the day started early with tai chi led by an experienced instructor. The session was suitable for novices and experienced tai chi practitioners. If you have not tried tai chi as an exercise for your AS, you should! It emphasises posture, core strength, stretching and flexibility.



Following breakfast, the first day of the Council Meeting got under way with the President, Zhivko Yankov, welcoming everyone and the delegates and observers introducing themselves. After this, some

business of the Council Meeting was conducted. This is recorded separately in the Minutes of the Meeting.

The first speaker of the day was Ricky White, President of the US charity Walk AS One, which runs the annual Walk Your AS Off event. Ricky's background is in nursing and software development. Ricky was diagnosed with AS in 2010, which prompted him to become a patient advocate and voice for awareness of the disease.

Social Media Campaigning and Walk AS One



Ricky White, U.S.A., President, Walk AS One, Author, Software Developer, AS patient.

Ricky explained that he is covering these two topics, the first because he is a community manager for Real Python (see www.realpython.com), which has substantially grown its social media presence on Facebook and Twitter and now receives over one million page views per month on its website; the second because he is a founding member of Walk AS One.

Ricky said that it's obvious that social media is important, with Facebook being the most active social media in the world with 2.2 billion users. YouTube has 1.9 billion active users, Instagram 1 billion and Twitter 336 million. But to use social media effectively you have to promote your product or service, promote brand awareness and promote community.

When you are planning a social media campaign you have to define the Who, What, Why, Where and When. Who is the target? Be as specific as possible. What is the objective and call to action? Be careful to make it

only one call to action! What does success look like? Why should people care and what is the message? Where is it happening, in person or online? When is it happening? Determine dates, time, place and length of the campaign.

The plan around a social media campaign should consider what content is going to be posted, the frequency of posts (and remember to give, give, give, and then ask! Or, using a boxing analogy; jab, jab, jab, then right hook!), whether you have the appropriate images and assets, and will you use video. It's also important to determine how to monitor the progress of the campaign and which tools to use. For example, some posts can be automated to go out at pre-scheduled times.

The implementation of a social media campaign calls for you to connect with the target audience on a personal level. Make it about *them*, not you. Live video is becoming increasingly important, so consider using it. Also ensure your campaign is mobile friendly. Most people use social media on their smart phones, so your campaign needs to have great mobile user experience and great mobile user interface. Lastly, will you use paid advertising for your campaign? It can be very effective, but Ricky advises to educate yourself first about paying for advertising.

Once you have implemented your campaign, if you can't track it you can't determine if it was a success. To allow you to track your campaign, use hashtags correctly, use Google Analytics and link shorteners and tracking. You'll have to consider any platform restrictions to tracking, and privacy and privacy settings.

At the end of the campaign, you should evaluate what worked and what didn't. What feedback did you receive? Did you meet your idea of success? Ricky gave two examples of campaigns that worked very well, the 2014 ALS Ice Bucket Challenge, which created a lot of awareness and raised \$115 million in eight weeks, and the 'Know Your Lemons' Breast

Health Education campaign, which reached 116 million people around the world.

Ricky provided some social media resources covering research, tracking, automation and licence-free images, and concluded this part of his presentation by saying that in any campaign there are two words to always remember, Trust and Story (or Narrative). If you have any questions about the presentation, contact Ricky at ricky.white@walkasone.org

The second part of Ricky's presentation covered the history of Walk AS One, how it helps the AS community and its future plans. Walk AS One is a registered charity in the U.S.A., founded in late 2015 to further promote the Walk Your AS Off event that was started by Jennifer Vischer in 2012, as well as to administer more walks and events that are planned for the future.

The mission statement of Walk AS One is "Walk AS One mobilizes and motivates a global community to raise awareness and address the challenges of everyone affected by Ankylosing Spondylitis and its family of related diseases". Its goal is to increase the users of Walk Your AS Off (an event that was endorsed by ASIF in 2014). To achieve this, Walk AS One has a brand new website coming for Walk Your AS Off, which will allow team captains to message their team, keep proper track of steps achieved and be more user friendly. Participants in Walk Your AS Off in future will be motivated to achieve badges and earn gifts, among other ideas.

Ricky's presentation was followed by lunch and the opportunity to network.

Workshops – Session 1.



After lunch, four workshops were held. The attendees were split into four groups so that each group could rotate through all four workshops, spending about 20 minutes on each topic.

The workshop topics were:
(Facilitators in brackets)

1. Social Media Campaigning (Cassie Shafer, U.S.A.)
2. Raising Awareness among Medical Professions (Andri Phoka, Cyprus)
3. World AS Day (Michael Mallinson, Canada)
4. What can ASIF do to support its members? (Raj Mahapatra, U.K.)

The workshops generated lively discussion and many good points were raised. The workshops were an opportunity for all attendees to participate and make their voice heard on subjects that are important to ASIF and member organizations. Each facilitator was required to summarize the sessions they led with three actionable items that ASIF can take. The actionable items are detailed below. A further separate report will be made available with more of the points from the workshops.

1. Social Media Campaigning.
 - Create basic standards for social media to share with members.
 - Create key topics for World AS Day to share with members.
 - Use tools such as Thunderclap to create awareness of AS.
2. Raising Awareness among Medical Professions.
 - Target General Practitioners.
 - Target Medical Students.
 - Target scientific meetings.

3. World AS Day.

- ASIF to pre-plan World AS Day activities and messages with a clear objective.
- ASIF to co-ordinate messages among members for World AS Day.
- ASIF to share all activities and messaging around World AS Day with all members and stakeholders.

4. What can ASIF do to support its members?

- Create a tool kit for members covering best practices.
- Share information, news, success stories and lessons learned.
- Create Interest Communities to collaborate on webinars, conferences, etc.



The workshops were followed by a coffee and exercise break.

The European Map of AS – EMAS Project.

Prof. Marco Garrido Cumbrera, Health and Territory Research, University of Seville, Spain. AS patient.

The purpose of the EMAS project is to understand the patient perspective of living with AxSpA. Phase I of EMAS covered 13 European countries. Phase II covers Canada, some Latin American countries and several Asian countries. The EMAS project was originated by CEADE (Coordinadora Española de Asociaciones de Espondiloartritis), Marco and the Health and Territory Research group, University of Seville, and is sponsored globally by Novartis.

The results of the EMAS project are confidential at present. As soon as they can be distributed, ASIF will let you know. What follows below is a general review of Marco's presentation.

Marco explained that the objective of the EMAS initiative is to analyse the situation of people with AxSpA, to create a document that deepens knowledge of the disease and contributes new information aimed at improving patients' health care and quality of life. The initiative has been undertaken by surveying AxSpA patients after a literature review and with the input of European and National steering committees. The survey itself is split into different sections such as socio-demographic characteristics, employment status and income levels, diagnosis, health care and treatment, disability and performance, other disorders and disease. From the survey results a lot of information can be drawn, such as the number of years from disease onset to diagnosis, mean age at onset and the physical and psychological impact of AxSpA.

Questions related to BASDAI (Bath Ankylosing Spondylitis Disease Activity Index) showed that survey respondents had active disease. They also reported sleep disorders, anxiety and depression. Co-morbidities were common and generally, people with more comorbidities had more active disease and those with more active disease were more likely to experience psychological distress and have more difficulty finding a job.

AxSpA symptoms limit survey respondents' abilities to carry out daily and desirable activities and negatively affects relationships. What patients fear the most are, pain, loss of mobility and disease progression. What they hope for are effective treatments to eliminate pain and stop disease progression.

Conclusions that may be drawn from the survey are that despite improvements, the delay in diagnosis is still too long; that active disease limits the quality of life of patients and their professional opportunities,

and that active disease and psychological distress in diagnosed patients highlights key areas of opportunity in optimizing their care.

The final conclusion is that co-creating solutions among all stakeholders will improve the quality of life and standard of care for AxSpA patients.

Subsequent to the Council Meeting, Marco and Pedro Plazuelo, president of CEADE, presented two posters with some results of the EMAS survey at the American College of Rheumatology annual meeting in Chicago. These posters were Abstract numbers 638 and 1653 dealing with respectively, diagnostic delay and psychological distress in AxSpA patients. They can be accessed here:

Abstract 638: <https://acrabstracts.org/abstract/diagnostic-delay-and-associated-factors-in-axial-spondyloarthritis-across-europe-results-from-the-european-map-of-axial-spondyloarthritis-survey/>

Abstract 1653: <https://acrabstracts.org/abstract/psychological-distress-in-patients-with-axial-spondyloarthritis-in-europe-results-from-the-european-map-of-axial-spondyloarthritis-survey/>

Results of the original ATLAS survey conducted in Spain, can be found here:

https://espondiloarthritisaxial.org/atlas/img/AtlasEA_2017_v5-C_LQ.pdf

Following Marco's presentation there was a brief exercise break.

ASIF Members' Reports – Part 1

For this Council Meeting, all members had been invited to present something about their history, work or initiatives in any format they chose. The presentations proved to be of great interest. It is amazing what some members are doing!

1. **Coordinadora Española de Asociaciones de Espondiloartritis (CEADE), Spain**, presented by Pedro Plazuelo.



CEADE represents 23 associations in Spain, with 3,500 patients, a far fewer number than Pedro would like to see. CEADE has been working with rheumatologists and others to raise awareness of AS. Some projects are “Spondylitis With A Future”, a project to transform patients’ lives by improving their quality of life, and “Spondylopaedia”, a glossary of terms for AS and PsA patients.

CEADE has a closed Facebook group with 4,500 patients and professionals. It offers peer-to-peer support plus professionals respond to queries too, offering evidence-based support.

Other initiatives include “Look After Your Back”, an online screening tool and on You Tube, there is an ATLAS video.

2. **Bekhterev Norge, Norway**, presented by Odd Mikkelsen.



Bekhterev Norge has 11 local member associations and holds a national congress in April each year. The most popular activity for patients is pool therapy, in pools that are maintained at 34°C. Warm therapy pools are under threat of being closed down. The group has advocated against this but in one case was unsuccessful, meaning patients were deprived of a useful and popular therapy.

Patients are offered peer-to-peer support by telephone and email. Patients can travel to the Canary Islands in winter to be in a warmer climate. This is considered a therapy and, in fact, Bekhterev Norge is cooperating with Institutt Igalo to research the benefits to AS patients of a warmer climate.

World AS Day was celebrated by a walk around Oslo. Bekhterev Norge participates in EULAR, finding it a useful resource for the latest research.

To show just what a Norwegian winter is like and how they exercise in it, Odd showed photos of both he and Jon Hagfors shovelling snow off their rooves!

3. **Schweizerische Vereinigung Morbus Bechterew (SVMB), Switzerland**, presented by René Bräm.

SVMB is celebrating its 40th anniversary this year. It has 4,000 members. It offers therapy courses, travel and events (such as patient seminars), research, legal case management (on social security issues and workplace difficulties), information (includes a regular magazine 'Vertical' and an online screening test:



www.ruggeweh.ch and a forum for the exchange of experiences. It has exercise groups and has produced 'Rheumafit', a set of 200 exercises that can be tailored to individuals depending on their condition. The user can filter the exercises to find the program best suited to themselves. SVMB wants to be able to provide Rheumafit to physiotherapists.

You can find Rheumafit here: <https://rheumafit.ch/> In addition, SVMB's website is www.bechterew.ch and is available in German, and French with part in English.

Following Part 1 of the Members' Reports there was a little free time before everyone met at a bus at the hotel entrance to be taken to a welcome dinner at the Dong Fang Hotel.

The dinner was not only to welcome ASIF delegates, observers and guests, but also to celebrate the 40th anniversary of the Rheumatology and Immunology Department of the Third Affiliated Hospital, Sun Yat-Sen University, Dr. Gu's hospital. All guests were entertained to an evening of Lion Dancing, plus the medical students and nurses at the hospital put on shows of Spanish dancing and Chinese singing. A choir of rheumatology patients sung too, while a highlight of the evening was sand painting telling the story of ASIF. The dinner provided was a wonderful banquet of Chinese and local Guangzhou dishes.



DAY 2 - Friday, 12 October.

The second day of the Council Meeting also got underway with early morning tai chi for those who wanted. Others took advantage of the spa and swimming pool in the hotel.

The first Agenda item of the day was a presentation given by Bo Jiang.

Introduction to AS in China.

Bo Jiang, China, Executive Vice-President of the Chinese AS Patient's Society and China Health Promotion Foundation.



Bo's presentation started with an introduction to the Chinese AS Patients' Society, which was founded in 2011 by Dr. Jieruo Gu, who is President of the Society, and two other prominent doctors. We were shown photographs of the first few meetings of the Society and told that the focus of these early meetings was the relationship between doctors and patients and to see what the Society could do to help patients, particularly those who needed surgery but who couldn't afford it. Much of the discussion was driven by Dr. Gu's wish to see all the resources of patients, doctors and researchers combined to help patients. This includes looking after patients' mental health.

Seminars are offered by the Society, at which patients learn how to deal with their chronic disease and their mental problems. In China, patients have little knowledge of AS and many are diagnosed late in life after they have suffered damage from the disease. Dr. Gu and the Society want to see people with AS diagnosed much earlier so that people do not have the same hip problems that are currently evident.

Because so many people have severe, untreated or improperly treated AS there are many people who need hip surgery to improve their quality of life. (Dr. Khan later advised that there is more severe AS in China because of the high prevalence of HLA-B27 Subset 4, a subset that causes more severe disease.) Bo showed a video of a patient before and after surgery. The difference to the patient was astounding. From being very bent over, he was able now able to stand upright and look straight ahead. Because of the number of patients requiring hip surgery, the patient society, working with an affiliated charity known as the Chinese Health Promotion Foundation, concentrates on providing hip surgeries, about 50 a year, to patients who need it. Each operation costs about US \$10,000, which means that most patients cannot afford it.

The Foundation also seeks the best surgeons in order to reduce the risks of hip surgery. This is important because any errors can harm the reputation of the Foundation, which spends a lot of time in trying to build up a relationship of trust between patients and doctors. It is because of this trust that the Foundation does not do back surgery. It is too risky. Successful hip surgeries are used to show other patients examples of how their lives can be improved so that they become comfortable with the idea of surgery. Bo believes that the best thing for patients is to see other patients doing well and living well with AS after hip surgery.

Other activities of the Society include putting on seminars to inform patients, accepting the donation of bicycles (which are given to patients to help improve their exercise regimes), co-operating with other disease areas and working with Chinese Traditional Medicine, which Bo believes is effective.

In addressing the challenges the Society faces, Bo advised that although the Government is supportive of the Society, raising money is an issue that requires the monetary support of the Government, corporations

and individuals. Going back to Dr. Gu's wish to see all stakeholders combine their resources to benefit patients, there is a challenge in how to achieve this and build the necessary relationships. There are also challenges in creating more awareness of AS, in providing more material, books, magazines, etc. for patients and in the number of rheumatologists available to treat patients.

Bo's presentation was followed by Questions and Answers. One question dealt with the effectiveness of Chinese Traditional Medicine and AS. As Bo said in his presentation, he believes in the effectiveness of Traditional Medicine. A discussion amongst attendees after Bo's talk on this topic had many feeling that the effectiveness was in treating symptoms of pain, fatigue, etc., but not in dealing with the underlying disease. Bo had inferred in his talk that part of the long delay in diagnosis was because people were taking traditional medicine and were thus alleviating symptoms but without stopping the damage of severe disease.

Another question was why the Society was concentrating on older patients with late stage AS instead of promoting early diagnosis. Bo's answer was that there is a lack of knowledge of the disease and medical resources are spread unevenly. There's a limited number of rheumatologists and they are concentrated in urban areas. While China has a lot of elderly, late-stage patients who need help, the Society is trying to educate physicians and patients about early stages of AS.

Member Reports – Part 2

1. Canadian Spondylitis Association, Canada.

Presented by Gerald Major.

Gerald provided a brief overview of the Canadian Spondylitis Association including its awareness, support, education and advocacy work. Most of the presentation was given over to a recent comorbidities survey conducted by the Association and presented as a poster at the 2018 Cochrane Colloquium. The survey attracted 406 responses of whom 83% of respondents had AS and the balance another form of SpA. 73% of respondents were female. Chronic pain and mental health issues were reported by over 50% of respondents and 50 of the AS patients reported having multiple SpA conditions. The survey showed a direct link between mental health and increased reporting of chronic pain, chronic fatigue and sleep disorders.



The four most commonly reported complications were chronic pain, depression and anxiety, Crohn's and colitis, and uveitis. The survey results showed that on average people with SpA live with four other conditions. In addition to those mentioned, these include sleep disorders, chronic fatigue, psoriasis and hypertension.

The survey also looked at which condition was diagnosed first, AS (55% of the time) or a comorbidity (45%), and which health care professional first suggested AS. In about 35% of cases it was a family physician who first suggested AS, followed by

physiotherapists, chiropractors, ophthalmologists and massage therapists.

Exercise and diet/nutrition were the most followed non-pharmacologic treatments, but these treatments also included massage therapy, mindfulness, spirituality and medical cannabis.

The challenges faced by the Association include awareness, particularly amongst non-specialist health care professionals, the time to diagnosis and rheumatologists buy-in in referring their patients to the Association. Challenges also come in fundraising and engaging patients, particularly men and the younger age demographic.

One initiative the Association has undertaken is developing website content on each comorbidity or condition in partnership with other specific disease organizations, and sharing this information with referral information on each other's websites.

Treat To Target ('T2T') in Ankylosing Spondylitis

Dr. James Cheng-Chung Wei, Taiwan, Attending Physician and Professor, Chief of the Division of Allergy, Immunology and Rheumatology and Director of the Chinese Medicine Clinical Trial Centre, Chung Shan Medical University.

James introduced himself as a rheumatologist and AS patient, who has been an author in over 120 scientific papers and a principal investigator in 80 clinical trials. James advised that



the Taiwan AS Caring Society was founded in 1996 and has 1,000 members who pay a membership fee of US \$40 p.a. James mentioned getting other funding is difficult.

James' presentation was in four parts:

1. Why do we need a treatment goal? There's a need for a treatment goal in any disease. T2T has been successful in diabetes and hypertension. In 2009 T2T was introduced in Rheumatoid Arthritis and in 2012 for AS.
2. What is the treatment goal? It's a difficult question in AS because it is hard to define Spondyloarthritis. The primary goal in AS should be to maximise long-term health related quality of life in patients through the relief of symptoms. The complexities of dealing with this question are set out in an T2T article that James co-authored that can be found here:

<https://ard.bmj.com/content/73/1/6.altmetrics>

The first aim of T2T in AS should be to achieve an ASDAS (AS Disease Activity Score) of no more than 2.1. James points out that there are two treatment goals in SpA, either remission or alternatively, low disease activity, especially for those with long disease duration.

3. How to assess the patient? ASAS (Assessment of Spondyloarthritis International Society) has an ASAS app that is an ASDAS calculator. (The ASAS app is available through the App Store or Google Play in 13 languages.) ASDAS results need to be interpreted in light of pre-selected cut-offs for disease activity.

James noted there is a longitudinal relationship between ASDAS and mSASSS (Modified Stoke Ankylosing Spondylitis Spine Score), which means that over time ASDAS and mSASSS show the same changes in disease activity. In T2T, there is also the ASAS Partial Remission Criteria to consider. This is measurable and reflects very low disease activity, such as the partial remission seen in patients with early AxSpA who are treated with infliximab.

4. Practical Issues. There is a need to target remission or an ASDAS of less than 2.1, with an assessment every three months. Phase 1 of T2T in SpA means managing the patient in accordance with the ASAS/EULAR 2016 management recommendations (conventional therapies of NSAIDs, COX-2 inhibitors and csDMARDs (conventional synthetic disease modifying anti-rheumatic drugs)). Phase 2 means trying biologics, with a need to still monitor progress every three months. Phase 3 means trying another biologics if the first biologic fails, with an evaluation every three months. James noted that in some Asian countries biologics are not readily available. Also, that if the treatment target (BASDAI less than 4 or ASDAD less than 2.1) is not achieved in each of the phases, then you move forward to the next phase. If biologics unfortunately do not work, you have to look at alternative and experimental therapies, such as the emerging small molecule therapies.

If the T2T process extends beyond 6 months there is a step-down strategy that can be tried. There are three steps; treat to target, taper and monitor. In other words, if with T2T a patient achieves low disease activity for six months or more, then tapering off the biologic can begin whilst the patient's progress is monitored. Of course, if there is a relapse, T2T has to be implemented again.

In summarizing his presentation about treat to target, James noted that the doctor and patient should communicate frequently about the treatment goal. Clinical activity should be assessed by monitoring BASDAI and ASDAS_{CRP} (C-reactive protein (CRP)-based ASDAS) every three months, and the T2T strategy should be used in disease management for better outcomes. Most importantly, there should be holistic care of AS, looking after the spine, joints, entheses, extra-articular manifestations and targeting the mind and spirit also to ensure a healthy social life.

Following Dr. Wei's presentation there was a coffee and exercise break.

Emerging therapies in AS.

Dr. M. Asim Khan, U.S.A., Professor Emeritus, Case Western Reserve University, author, AS patient.

Asim started by talking about the genetic associations and treatment of AS. Most are familiar with the TNF molecule, which is the target of anti-TNF biologics. But as their involvement with AS becomes better understood, other genes and molecules associated with AS are being targeted, such as Interleukin 17 (IL-17), which is targeted by the biologic secukinumab.



It is understood that an excess of IL-23 leads to enthesitis and subsequent arthritis including sacroiliitis, osteoproliferation (bony formation), inflammation and bone loss (despite the bony fusion of osteoproliferation). Where is this excess IL-23 produced? It is observed in the gut of AS patients, where IL-22 production is regulated by IL-23 to protect gut mucosa (mucous membrane). So, the sub-clinical gut inflammation observed in AS patients is characterised by an over-expression of IL-23.

The enthesis is the region at the junction between tendon and bone and has been suggested to be a key target in spondyloarthritic diseases. This zone is now shown to contain a unique population of resident T cells, which, when activated by IL-23, can promote pathogenesis (origin and development of disease) that is characteristic of Spondyloarthritis. There is more on this in an article by Lories, RJ et al that can be found here: <https://www.nature.com/articles/nm.2854> (The full article is subject to a pay wall.)

It takes a long time for a new drug to come to market. In the case of ustekinumab targeting the P40 subunit of IL-12 and IL-23, it was

discovered in 1989-91 but was approved in the U.S.A. only in 2009. It is approved for psoriasis and Psoriatic Arthritis but not for AS because it didn't work for AS.

AS is characterized by two key pathological findings: inflammation at the enthesis (the connective tissue between tendons, ligaments and bone) and new bone formation. Newer treatments that act on the enthesis include secukinumab, which targets IL-17A and is approved for PsA and AS, and ixekinumab, which also targets IL-17A and is approved for PsO and PsA with approval pending for AS. Bimekizumab, which targets IL-17A and IL-17F, is currently in a Phase 2b study for AS patients.

TNF Inhibitors and IL-17 drugs have been found to be very effective in treating some patients but not all. It brings up the question of why not try to combine the two drugs? There is some work being done in this regard.

Progressive bony fusion is a consequence of AS. This bony fusion does not slow down with the use of NSAIDs over five years. But with secukinumab there is a dramatic slowdown. About 80% of tested patients taking secukinumab showed no radiographic progression of their disease over two years.

Newer treatments for AS and PsA include non-biological, small molecule agents. Tofacitinib (brand name "Xeljanz") is a JAK inhibitor taken orally for psoriasis and which is now undergoing trials for AS and PsA. Apremilast (brand name "Otezla") is a PDE4 inhibitor taken orally, approved for PsA. Unfortunately, a Phase III trial for AS did not show efficacy. Upadacitinib is a JAK1 inhibitor under investigation for PsA.

Asim explained that two of several factors that influence inflammation in SpA are the cytokines milieu, addressed by the drugs already discussed, and an altered microbial composition. In other words, AS is

affected by the patient's gut microbiome. Patients with HLA-B27 have less microbiome (fewer microbes or bugs!) in their gut than those without the gene. It is thought that by increasing the microbes in the gut, AS can be treated. One way of increasing the number of microbes is to eat probiotics. Unfortunately, a clinical trial and internet-enabled study showed no efficacy of probiotics in AS. Prebiotics are another way of inducing the growth of microorganisms. There have been no studies of Prebiotics and AS to date. Antibiotics are also thought to have some effect on the microbiome. In the case of AS, a trial of the antibiotic moxifloxacin in patients did not affect those patients' ESR and CRP.

What does affect CRP rates is smoking. Smokers have elevated CRPs compared to non-smokers and the incidence of AS (and hypertension) has been found, in a Norwegian study, to show an association with smoking. This suggests that smoking should be discouraged in unaffected individuals who are at a higher risk for AS, for example those with the HLA-B27 gene or with a family history of AS.

Asim finished his presentation with a review of the SpA landscape, talking of the associated manifestations and comorbidities of AxSpA such as uveitis, skin psoriasis and nail changes, gut involvement and lung, heart and kidney involvement. Some of these extra-articular manifestations and comorbidities may require a multi-disciplinary approach to AS management. One chart Asim showed was of particular interest. It showed that the Male to Female patient ratio in Switzerland had fallen from 2.6:1 in 1980 to 1.1:1 in 2018.

In his concluding remarks, Asim said that SpA is much more common than previously thought and that SpA forms a heterogeneous group. Early diagnosis is important for maximizing the patient's quality of life and for slowing down their disease progression because of the more effective treatments available today. Lastly, there is a crucial need for

closer cooperation between health care providers to ensure early referral and diagnosis of AxSpA patients.

Dr. Khan's presentation concluded the morning and was followed by a lunch break. After lunch, workshops were held as detailed below. The main action items are also given. While four workshops were scheduled, it was decided not to run one, on ASIF support for its members, because the topic had been thoroughly covered yesterday.

1. How to encourage rheumatologists and other health professionals to recommend membership of a patient organization. (Wendy Gerhart, Canada)

- Build trust and respect with HCPs.
- Networking and attending conferences.
- Approach medical students.
- Patient award for rheumatologist and team.

ASIF action: build a toolkit for members.

2. How to engage young people and keep them engaged. (Eva Nasková, Czech Republic)

- Use mobile and digital space frequented by young people.
- Raise awareness of AS and change young people's perception of arthritis.
- Special programs such as Lunch & Learns.

ASIF Action: Create an Interest Community.

3. Building relationships with pharmaceutical companies. (Annie McPherson, Australia)

- Understand what pharmaceutical companies can/cannot do.
- Understand what pharma companies will/will not fund.

ASIF Action: Create guidelines for relationships with pharmaceutical companies.

The workshops were followed by a presentation:

Shared Decision Making and Personalised Treatment, Part 1.

Souzi Makri, Cyprus, President of ENFA (European Network of Fibromyalgia), Past Chair of AGORA, Vice-President CYPLAR (Cyprus League Against Rheumatism), EUPTI Fellow and author.

The presentation started with a short video (www.youtube/watch?v=eAaTnGkbpPc) about what shared decision making is. Shared decision making is a conversation between a physician and the patient where the physician provides the patient with options regarding his/her treatment, so that the patient can select which option best fits their own goals and preferences. Shared decision making occurs at the intersection of three areas of consideration: (1) the patients and family's goals and preferences, (2) the clinician's expertise and the medical evidence, (3) the biological, psychological and sociological context.



There are challenges to shared decision making, particularly the paternalistic view of some physicians but also the fact that patients are not informed and empowered enough to fully participate in the process. To remedy this AGORA has produced a Quick Reference Card to facilitate communication between the patient and the health care professional. The card can be found here <http://www.agora-pait.com/downloads>.

The card has a tip for communication: PART, which stands for **P**repare, **A**sk, **R**epeat, **T**ake Action. Details of each PART are on the card.

To also assist patients, Souzi spoke about EUPATI (European Patients' Academy on Therapeutic Innovations), a public-private partnership with a key initiative to build competencies and expert capacity amongst patients. Further to this, in Cyprus a self-management program to inform, educate and empower patients has been implemented. Its objectives are to provide information on rheumatic diseases, to train patients in how to deal with everyday challenges, communicate with health care professionals and stay active members of society.

The program is run as a five week course with specific topics every week, facilitated by trained trainers.

Turning to Personalized Treatment, also called Precision Medicine, Souzi advised that it is a medical procedure that divides patients into separate groups with medical decisions and practices tailored to the individuals in each group, based on their predicted response or risk of disease.

In concluding, Souzi said that shared decision making is right for patients, that each one of us is unique, and that treatment should be personalized to each of us according to our disease state and activity, phenotype and life style. Additionally, patient organizations should work to educate and empower patients so they can be equal partners in deciding on their treatment.

After Souzi's presentation there was a coffee and exercise break.

Shared Decision Making and Personalised Treatment, Part 2.

Souzi Makri, Cyprus, and Andri Phoka, Cyprus, Secretary of ASIF, General Secretary, CYPLAR, Board Member Cyprus Federation for Disabilities and the Cyprus Patients Federation.

Instead of holding the scheduled workshops on Personalized Treatment and Shared Decision making, Souzi was joined by Andri Phoka in three

patient/physician role-plays to illustrate three different types of interaction between a physician and a patient. After each role-play there was a discussion of the type of interaction, its pros and cons, the messages hidden in body language and the outcomes of the interaction. Souzi and Andri proved to have excellent acting skills and the role-playing was a clear message about the types of interaction portrayed.



Following this item of the Agenda, Raj Mahapatra (U.K.) led everyone in an exercise break.

The last presentation of the day covered two topics:

The new criteria for Axial and Peripheral Spondyloarthritis plus co-morbidities.



Dr. M. Tuncay Duruöz, Turkey, Professor Medicine, Head of Rheumatology Division, Mamara University Medical School, Professor, Eastern Mediterranean University School of Medicine, Cyprus. President of TLAR (Turkish League Against Rheumatism) and President of ASHAD (Turkish AS Patient Society). ASIF Trustee and author.

In opening his presentation, Tuncay talked about the clinical manifestations of SpA, which is a group of diseases sharing common and clinical features. The clinical manifestations include involvement of the spine, entheses, fingers, eyes, skin and bowel, and usually, the presence of HLA-B27. Under the old classification criteria there was a group of diseases called AS, PsA, Reactive Arthritis, Juvenile Idiopathic Arthritis that is enthesitis related, arthritis associated with inflammatory bowel disease and undifferentiated SpA. The new classification puts everything under the umbrella of Spondyloarthritis and then divides SpA into Axial and Peripheral SpA depending on the predominant clinical manifestation.

Tuncay then reviewed some of the existing classification criteria for SpA, including the Amor (named after the author), ESSG (European Spondyloarthropathy Study Group) and Modified New York Criteria. Each were developed before MRI imaging and depended on a list of conditions being met.

With MRI imaging new criteria needed to be developed because MRI could spot what is termed non-radiographic axial SpA, in other words persistent back pain with evidence of sacroiliitis on MRI but not on x-ray. ASAS developed new criteria for Axial Spondyloarthritis that applies to patients who have had persistent back pain for three months or more and who are under age 45. The criteria calls for imaging, MRI or x-ray, to show sacroiliitis plus one or more of 11 listed SpA features, or, if there is no imaging, the patient must be positive for HLA-B27 and have two of the listed SpA features.

The ASAS AxSpA Criteria are highly sensitive and specific, showing better specificity to the old criteria and equal sensitivity. While the term AxSpA covers a continuum of disease activity, the history of nr-AxSpA is still largely unknown and many patients with nr-AxSpA may never develop AS. The role of imaging in diagnosing AxSpA is pivotal.

The long delay in diagnosis is mainly because of the old need to see sacroiliitis radiographically. MRI is now expected to enhance diagnostic accuracy in the early stages of disease.

ASAS has also developed new classification criteria for Peripheral SpA. The classification criteria were tested in a worldwide ASAS-COMOSPA (COMOrbidities in SPondyloArthritis) study, where all patients had to fulfil the ASAS AxSpA or ASAS pSpA criteria. In addition, they were then assessed using ESSG, mESSG, Amor, mAmor and CASPAR (Classification criteria for Psoriatic Arthritis). The results showed that patients fulfilling the clinical arm were remarkably similar to patients fulfilling the imaging arm with respect to the presence of most SpA features. This suggests that all the ways of classifying SpA are pretty good and the use of each seems to give the same result, so the criteria for SpA are credible. It also suggests that rheumatologists worldwide use a similar picture of what SpA is.

However, to further verify the ASAS classification for AxSpA and pSpA, several researchers undertook a systematic literature review and meta-analysis. The accumulated evidence from studies with more than 5,500 patients confirms the good performance of the various ASAS SpA criteria as tested against the rheumatologist's diagnosis.

Does this mean the ASAS classification criteria are perfect? No, there are limitations. Because of the lack of diagnostic criteria, physicians may inappropriately use the ASAS classification criteria for diagnosis, leading to over-diagnosis of SpA. Also, all items in the classification criteria have equal weight, whereas in clinical terms the importance of subjective and objective features may differ. There are a number of reasons that it may be time to modify the ASAS Classification Criteria. For example, the primary aim of classification criteria is to create homogeneous patient populations for basic and clinical research, but the multi-arm construct of the ASAS criteria is a potential source of

heterogeneity, which reduces their utility. There are other reasons. Patients with radiographically evident disease by the ASAS criteria may not have AS; many patients with nr-AxSpA may never develop radiographic sacroiliitis; there are differences between nr-AxSpA and AS and between the imaging and clinical arms of nr-AxSpA.

Tuncay now turned his attention to Extra-Articular Manifestations (EAMs) in AS and comorbidities in SpA. EAMs include uveitis, psoriasis, inflammatory bowel disease and cardiovascular, lung, neurological and renal features. Apart from these EAMs which are directly related to SpA, patients may also suffer from different additional conditions, referred to as comorbidities. Comorbidities contribute to the disease burden, prognosis, morbidity and mortality. Their prevalence in the SpA population is also high compared to the general population.

A large cross-sectional study of SpA patients in 22 countries showed the commonest comorbidities to be hypertension, hypercholesterolaemia (high cholesterol), osteoporosis and gastroduodenal ulcer. Osteoporosis is related to disease duration and ankylosis of the spine and puts the patient at greater risk of vertebral fractures.

Tuncay then ran through complications related to AS and their characteristics. Cardiovascular Disease (CVD) is an increased risk to patients with AxSpA because of the presence of inflammation. In fact, CVD is the leading cause of death in AxSpA patients, accounting for 30-50% of deaths. AxSpA patients should have regular cardiac assessments.

Ischemic Heart Disease (IHD) and Stroke are found in SpA patients, with an increased risk for both compared to the general population. There's also an increased prevalence of hypertension in SpA patients compared to the general public, making it the most frequent risk factor for CVD.

Gastroduodenal Ulcers are one of the most common comorbidities, with the ASAS COMOSPA study indicating 10.7% of AS patients have them. Lung disease is also a complication of AS, particularly in patients who have had AS longer than 10 years. A systematic review of ten studies showed a 61% prevalence of pulmonary abnormalities on chest HRCT (High-resolution Computed Tomography).

Renal (Kidney) disease, including kidney stones, affects about 3.4% of men and 2.1% of women with AS compared with 2% of men and 1.6% of women in the general population.

Cancer is a low risk for AS patients, with very little difference from the prevalence in the general population. Infection in SpA patients is also a low risk.

In concluding the second part of his talk, Tuncay advised that the incidence and prevalence of comorbidities in SpA patients differs from one country to the next due to lifestyle, socioeconomic conditions, eating habits, genetic differences, etc. But comorbidities are common. An ASHAD online survey found that 88.5% of responding patients had at least one co-morbid disease. Tuncay's own unpublished data shows that out of a list of 15 comorbidities, 36.2% of SpA patients have psychiatric disorders, 33.5% have ulcers, 31.5% have anemia, and 25.8% have liver disease.

What is to be drawn from the existence of so many comorbidities? Tuncay said that there needs to be a systematic screening for comorbidities to improve both the short and long-term outcomes for SpA patients. The assessment and management of comorbidities requires a multidisciplinary approach to the management of SpA patients.

* * *

At the end of a very long and informative day, everyone was then treated to a dinner in a restaurant at the top of the Canton Tower (Guangzhou used to be called Canton). The tower is 604 meters tall, making it the second tallest in the world. The restaurant is at the 104th floor, with spectacular views over the Pearl River. The tower itself is also a spectacle as during the night it emits lights, changes in colour sometimes is a rainbow of colours.



The dinner was greatly enjoyed. A visit to the toilet was not for the faint of heart, as the windows looked downwards (the tower is a narrow-waisted spiral and the restaurant is above the waist) to the ground and river 400 meters below!



More on the Canton Tower: <https://thetowerinfo.com/buildings-list/canton-tower/>

DAY 3, Saturday 13 October.

Once again the morning started with the option of tai chi, led by an instructor who had remarkable flexibility and movement.

After breakfast, the first business of the day was the election of ASIF Trustees. This is recorded separately in the formal Minutes of the meeting. We note that because ASIF is a charity registered in the U.K., it is governed by Trustees rather than Directors. We welcomed 3 new Trustees to the Committee, Cassie Shafer, Aleksei Sitalo and Yuki Zeniya.



Dr Gu with some of the Trustees of ASIF

ASIF Members' Reports – Part 3

1. Mutual Aid Society for Ankylosing Spondylitis, Russian Federation Presented by Aleksei Sitalo

Aleksei reported that holding the last ASIF Council Meeting in Moscow really kick-started the society, giving it visibility and credibility. The main purpose of the society is to improve the lives of its 5,000 members through information and education and social, mental and medical rehabilitation. The society has 20 regional departments, an increase from 12 in 2016. Over 10,000 people participate in its social networks.

The society's projects include educational forums for patients (2,500 people have participated in 30 forums), the promotion of exercise (a series of five video courses has been made available through 10,000 DVDs) and participating in scientific research.



One large project was an online screening test. It was developed with contextual advertising and financing from a pharmaceutical company. The test has been approved by experts. If the test results indicate AS, the person taking the test gets a document at the end that is an official referral to a rheumatologist.

The test can be found here:

<http://bbehtereva.ru/samodiagnostika/test-na-opredelenie-vospalitelnogo-kharaktera-boli>

Another large project is a mobile app. It will encourage self-management and will contain a course on AS. It will also have a health tracking tool as suggested by the Moscow Institute of Rheumatology to connect with younger people.

Some recent successes of the society were in getting Government financial support to develop the 'Schools for patients' forums, allowing for 10 forums in 10 different regions in 2017-2018, and in building six new regional departments of the society.

Further successes have been in providing legal assistance to patients, with 20 successful cases so far, and in getting the attention of policy makers, particularly as the Society advocates for the disability status of AS patients. The Society is advocating that

once an AS patient is qualified as disabled, they are so for life instead of having to re-qualify periodically. The importance of this to patients is because if someone is officially disabled, they receive free medications.

Lastly, Aleksei talked about a modified Ikea bed he has made to take to rheumatology conferences. Health individuals put on a jacket and lie on the bed. When they try to get up they find that they are stuck in bed by Velcro strips. This is to show them what trying to get out of bed with morning stiffness is like!

Aleksei asked ASIF for a letter addressed to the Russian Government regarding the importance of early diagnosis. It was proposed that ASIF should supply the letter and everyone was in agreement with doing so.

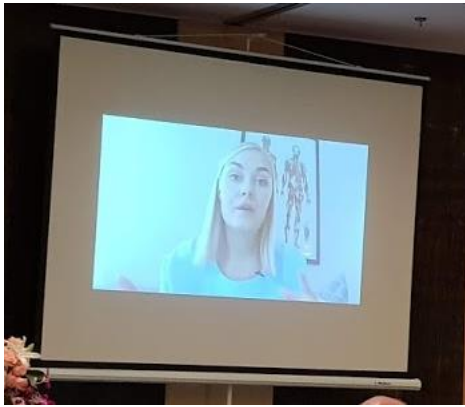
2. Foreningen for Rygsøjlegigt og Morbus Bechterew, Denmark

Presented by Mathilde Langballe Sørensen (Video)

Mathilde made the video for the Council Meeting because no-one from the Danish Association could make the trip to Guangzhou.

Mathilde is the youth ambassador for the Association. Aged 25, Mathilde suffers from AS, PsA and Crohn's and was hired to focus on young people, many of whom do not know about the Association. The Association has redone its website, and Mathilde blogs about issues of importance to youth, such as how to balance life with disease and education, something she is very familiar with as she is finishing a Master's degree in Law.

The Association recently held a large youth workshop, paid for by pharmaceutical company partners, at which a rheumatologist



spoke, a nurse addressed softer subjects such as quality of life issues, depression, and how to balance life, and a physiotherapist went through the most suitable exercises. It was an amazing day and something that the Association will do again.

The Association collaborated with other patient organizations in arthritis and auto-immune diseases to create an umbrella organization. A survey of patients of several autoimmune diseases was conducted and some projects derived from the responses:

1. 'One diagnosis rarely comes alone' in which videos of patient stories were made to be shared between the patient organizations.
2. 'See the wholeness' addressed to doctors to have them look at all conditions that a patient may have.
3. 'See the Symptoms' where a brand new website was made for all the auto-immune diseases. Users can select the symptoms they are experiencing and get a print-out to take to their doctor with suggestions as to what their condition might be. There has been a lot of success with this and very positive feedback. The website is <https://sesymptomerne.dk/>

De Autoimmune (The Autoimmune) network applied for and has received a grant of 2.4 million Euros for a pilot project on creating an Autoimmune Centre, the first in Denmark, which will initially concentrate on arthritis, skin and bowel conditions and evolve to other diseases in due course. People are being hired to set up the Centre.

3. Deutsche Vereinigung Morbus Bechterew e.V. (DVMB), Germany.
Presented by Martina Irrgang.



DVMB was founded in 1980 and has 14,500 members. Its executive committee is comprised of eight members, all of whom have AS. It has a staff of five plus a lawyer. It has regular contacts with GPs and hospitals. Every year it meets with SVMB and OVMB.

DVMB calls itself the German network to help AS patients to help themselves. It offers exercise groups, lectures and seminars, booklets and a quarterly journal. It also offers an internet forum, having Facebook pages and a You Tube channel. As a free service, it offers medical and legal advice.

DVMB has 14 Federal departments, each running meetings and seminars and providing education for group leaders plus financing for group activities. In addition to the Federal departments there are 350 local groups, who play suitable group sports and do group exercise under professional supervision. The local groups also offer social activities, counselling and emotional support.

In the last slide of her presentation, Martina pointed to an issue of declining membership over the past 15 years and questioned whether this was just a problem in Germany? It's clear from the age-structure graph of membership that Martina showed, that membership is mainly comprised of those over age 50. Maybe our workshop on engaging youth in patient organizations will provide some guidance to re-building membership.

4. AS Victoria, Australia.

Presented by Annie McPherson.



AS Victoria was founded in 2005 and has between 80 and 100 members. Its main activities are seminars and social events that allow people to exchange ideas and experiences. It is run by a committee of 10. Its objectives are creating awareness, advocacy and patient representation, exercise programs and peer support networks. Four times a year the group has an information table at outpatient clinics.

AS Victoria works with MSK Australia and uses some of its printed materials. It also cooperates with other patient organizations.

Annie mentioned Medikidz Comics, a global initiative by doctors to explain medical information to children, and showed the comic book for AS. See www.jumohealth.com for more information.

Annie also told us about a website, Medicine X, which stands for Medicine Explained. The website is produced by doctors and artists to explain, by storytelling in lay language, what particular diseases

or conditions are. The stories are based on real people and created in Australia and the U.S.A. Coming soon is a story 'Ankylosing Spondylitis Xplained'. See www.medicinex.com for more information.

5. Ankilozan Spondilit Hasta Derneği (ASHAD), Turkey.

Presented by Dr. Tuncay Duruöz.

ASHAD, which means 'shining a light on AS', was founded in 2003 and has 10,200 members on Facebook. The first physician-patient meeting was in December, 2004 and has since become an annual event with between 200-300 participants. Other meetings are held in smaller cities, advertised by putting up outdoor posters. ASHAD has also used a popular talk-show host to create awareness. It places volunteers in schools to spread the word. ASHAD joined ASIF in 2005. It has been in the press and in the journals of other AS organizations. It collaborates on research projects such as EMAS and a comorbidities study.

ASHAD runs exercise groups, including Tai Chi. In association with a university it participates in an intensive two day training course for the best practices management of societies.

6. Spondylitis Association of America (SAA), U.S.A.

Presented by Cassie Shafer.

Cassie started her presentation with the mission and goals of the SAA and then talked about the executive committee and Medical and Scientific Board. The SAA is adding various specialists to its Board, selected because they have to be engaged in the affairs of SAA.



SAA has about 5,000 paying members and a database of 40,000. It has 40 educational support groups in 25 states and is growing this number. It has 12 staff.

Highlights of the SAA's patient support program are its regular 'Spondylitis Plus' magazine, a monthly e-newsletter, a toll-free information line, its website www.spondylitis.org, its social network, educational materials, webinars and partnering on awareness with Dan Reynolds, a member of the band 'Imagine Dragons' who has AS.

Further highlights include SpA awareness and support videos in doctor's waiting rooms, in person and live-streamed patient educational seminars, a first responder training video and an online screening tool. Finally, there is S.W.I.F.T. (SpA Web Info for Teens): <http://www.teens.spondylitis.org/>

In terms of Mission advancement, the SAA is advancing science through the annual SAA/Bruckel Early Career Investigator Award; and by, amongst other things, seeding novel research that fills critical research gaps; by supporting the first ever epidemiology study conducted in the U.S.A. by the CDC (Centers for Disease Control and Prevention); and by holding unmet needs conferences on SpA at the NIH (National Institutes of Health).

The SAA is involved in physician education including working with ACR (American College of Rheumatology) and SPARTAN (SpA Research and Treatment Network) to update the SpA treatment guidelines they all developed in 2015.

The SAA is undertaking a marketing and communications strategy around its brand and engagement. This is built on a trusted

relationship with its stakeholders, which includes its funding partners (corporations, members, individual and family foundations, bequests, etc.).

Turning to the future, Cassie outlined what's on the horizon for SAA. In 2018-2019, SAA will have eight new brochures, increase its presence with non-rheumatology health care professionals, hold Lunch & Learns at colleges, translate the treatment guidelines to patient guidelines, update its online exercise program, redesign the S.W.I.F.T. website and do a pilot launch of its 1st Annual International Spondylitis Summit on 2-4 May, 2019.

7. Klub Bechtěreviků České republiky z.s, Czech Republic.

Presented by Eva Nasková.



Eva advised that the Club has 1,350 members in 13 regional organizations. Its goal is to provide information and support and to encourage exercise. Most members are over 60. Young people don't want to admit to their disease and be part of the older group. Funding for the Club comes 50% from Government, 10% from membership fees and the balance from fundraising.

The challenges of the Club are fundraising, engaging members in Club management, attracting volunteers and new, especially young, members. Its successes have been in its social events, spa treatments, its monthly magazine and participating in Walk Your AS Off. Among its activities, pool therapy is common.

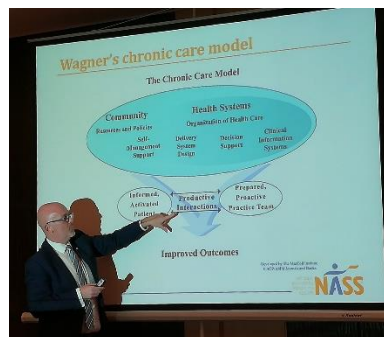
8. National Ankylosing Spondylitis Society (NASS), United Kingdom. Presented by Dr. Dale Webb.

Dale reported that the last year has been a time of significant change within the organisation. NASS has developed a new vision statement and, reflecting on recent policy developments in the UK, has also developed new strategic priorities.

The first of these is called Every Patient, Every Time. It includes the intention to develop a new Parliamentary committee which will have national oversight of the implementation of new national clinical guidelines. It also includes a new program called *Aspiring to Excellence* which will work with leading rheumatology services to develop a UK network of services that are working to achieve new performance benchmarks.

Dale also reported that NASS will be reviewing all of its information products in 2018, launching a national awareness campaign in the second half of the year and launching a new membership campaign.

The future that NASS wants to help create will see that every person with SpA will have timely and effective diagnosis, treatment and care; is empowered to make informed health choices, and feels part of a supportive community.



A coffee and exercise break followed Members' presentations.

The Importance of Exercise and How NASS Promotes It.

Dr. Dale Webb, United Kingdom, CEO of National Ankylosing Spondylitis Society.

Dale advised that the evidence of exercise has evolved. People are consuming health information in new and different ways and now have greater expectations about their health. The benefits of exercise in AxSpA are well-known but bear repeating: maintain or increase range of motion and flexibility, maintain or improve posture, improved sleep, better fatigue and pain management, maintain home and work activities, better self-esteem and mental health.

The NICE (National Institute for Health and Care Excellence) SpA Guidelines calls for physicians to refer their AxSpA patients to a specialist physiotherapist to start an individualised, structured exercise program, including hydrotherapy. See

<https://pathways.nice.org.uk/pathways/spondyloarthritis>

The ASA/EULAR recommendations for the management of AS also call for exercise and physical therapy. One problem with these recommendations is that in clinical practice there is a lack of information to guide exercise planning. But, a recent consensus statement was developed by physiotherapists in Australia, see www.sciencedirect.com/science/article/pii/S0049017215002012

Over the past 10 year physiotherapists' attitudes towards recommended exercise has changed. Instead of discouraging certain activities, physiotherapists now encourage what they like, giving consideration to the risks. This means that NASS must change its exercise recommendations and not say 'No' to some activities.

A recent study showed that 56% of people with AxSpA were not exercising at the time they were diagnosed. There are many barriers to exercise, such as pain, fatigue, work and home commitments, a dislike of exercise and lack of self-efficacy. How to overcome these barriers?

Dale suggests that the rise of digital health information can help. For



example, AxSpA apps such as NASS's Back To Action app. However, this is a first generation app, and a second generation app will be more interactive. The role of gamification (using smart phone games) may help overcome barriers to exercise. There

are some of these on the market, but none for SpA as yet. Another incentive may be VR – virtual reality – health information. Dale demonstrated, with his smart phone, how VR is being used in medical education and asked why not an AxSpA VR to be available to patients?

NASS is helping people to exercise by providing advice and information. It's important for people with AxSpA to believe that exercise will help them, particularly when it is counter-intuitive to think about exercising when you are in pain. NASS has 94 branches with supervised physiotherapy sessions, it provides lots of information on exercise and every Members Day includes activities and encourages members to try new ones.

A question and answer session followed Dale's presentation. It evolved into a discussion about the need for members to share much more information with each other, including sharing information on projects that members are undertaking.

My Story by Raj Mahapatra.

Raj is well known as the Chair of NASS, a Trustee of ASIF and as someone who participates in ultra-treks, running on mountain tracks. Raj started his story in 1993 when he was 21 and taking two hours to get up each day. He and his wife went to see a specialist. They found a waiting room full of old people and when they saw the doctor, he talked to them in terms they did not understand, then left the room and came back with two syringes. Raj asked what they were. The doctor replied that it was a 50/50 chance as to whether the injections would work and told Raj, given the active state of his condition, he would be in a wheelchair within 10 years. He then showed Raj to the door. Raj's wife baulked at this and asked the doctor for more information.



The doctor's response was to open the door wider, and say that he had patients waiting and couldn't afford the time!

Needless to say, Raj was astonished at the doctor's behaviour and words. He did not know how to take them and spent the next five years, three of them on crutches and two with a walking stick, without feeling any hope for his future. Raj now realizes that he was depressed.

Eventually Raj came to realize that he had a long-term chronic condition and began to devise his own ideas about what it meant to his life and how to deal with it. There was no moment of revelation, when Raj suddenly decided to do something. But he realized that he had to take a long-term view and he had to have a plan and goals to deal with his AS.

Raj had been a champion schoolboy sprinter and in fact his first symptoms started when he was 16. He was familiar with running and liked it. Looking for some exercise to manage his condition, Raj started running on mountains. It began to work. Raj explained that he has pain every day, which he calls bad pain. When he runs, he has good pain, which he can control and which masks the bad pain. He, and his wife, began to realize that his running was a form of pain management.

By embracing running as a way to manage his AS and pain, Raj saw that it opened new opportunities for him. And his plan is not to be beaten by his condition.

You can see Raj's story here <http://asif.info/projects/going-the-distance-raj-mahapatra-on-where-he-found-the-strength-to-overcome-as-and-keep-setting-himself-new-challenges/> and read more about it here: <http://runeatrepeat.co.uk/interview-raj-mahapatra/>

After Raj's story there was a brief discussion about the next Council Meeting. Council Meetings are usually held every two years so the next one is expected to be in 2020. The location is determined by whichever member organization volunteers to host the Council Meeting. There was some interest expressed by some members in hosting a future Council Meeting, but nothing definitive was determined for 2020.

If any member organization would like to host a Council Meeting or would like any information about doing so, please contact Jo Davies at office@asif.info.

With the conclusion of all the business of the Council Meeting, the afternoon was given over to a social program. Everyone was bussed to a restaurant for lunch. After lunch we were taken to the Guangzhou Museum, the Chenjia Ancestor Temple and Folk Art Museum and dinner on a river cruise boat.



The Guangzhou Museum had a wonderful display of old landscape paintings, the Chenjia Ancestor Temple displayed different forms of exquisite pottery, wood carvings and furniture. Walking to the river cruise took us through the stadium built for the opening ceremonies of the 2010 Asian Games in Haixinsha Park. The cruise itself was most enjoyable. Apart from the lavish buffet dinner, the sights on the Pearl River were amazing. Many of the buildings had light shows, including pictures of goldfish and lotus flowers moving from building to building. It was a warm evening that was thoroughly enjoyable.



After the dinner a bus took most people back to the hotel, but a few chose to walk back through the colourfully lit and thronged Flower City Square on a beautiful evening.

At the end of the evening, due to so many delegates, observers and guests leaving early on Sunday morning, everyone said their goodbyes to new friends and old after a very successful Council Meeting.

