

REPORT AND MINUTES OF THE 11TH ASIF COUNCIL MEETING, HELD IN

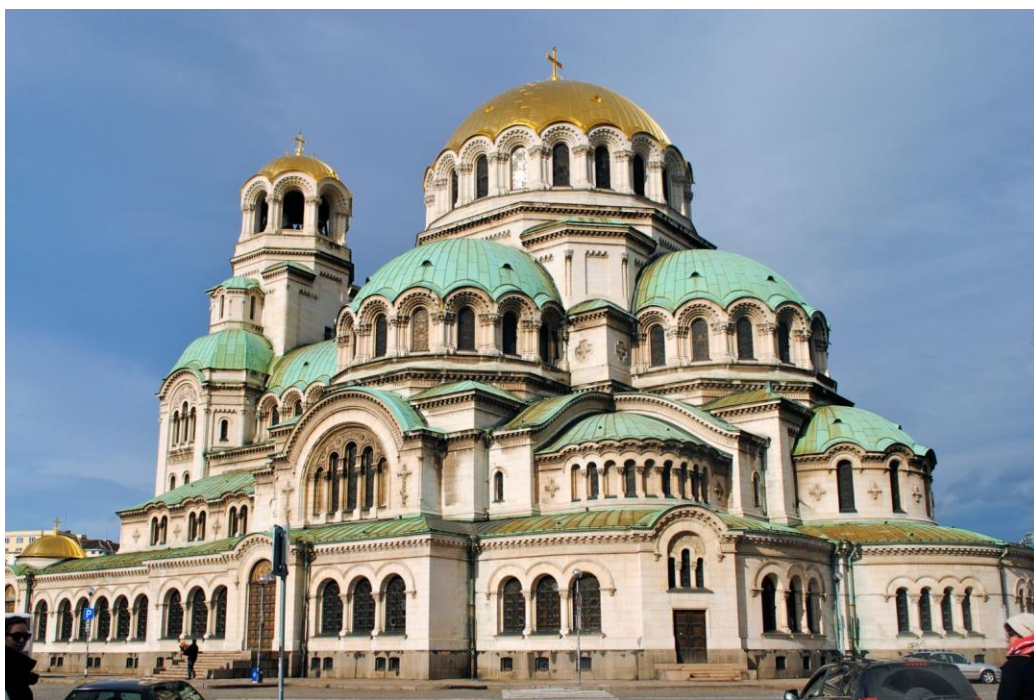
SOFIA, BULGARIA, 6-8 November, 2014.



Delegates from twenty countries to the 11th ASIF Council Meeting.

Thursday, November 6, 2014

Delegates arrived in Sofia and after being met in at the airport, were transferred to the conference hotel, the Ramada Sofia. As there were no formal events organized for the day, delegates and their guests were free to explore Sofia, shop, or just relax after their flights. For those who did go into town, the sights to enjoy were the Alexander Nevsky Cathedral, the parliament and government buildings and the central shopping area with department stores, restaurants and cafes.



The Alexander Nevsky Cathedral, Sofia.

In the evening everyone met for dinner and had the opportunity to reacquaint themselves with old friends and get to know new ones.

Friday, November 7, 2014

The formal council meeting started with the President, Seoirse Smith, calling the meeting to order, welcoming delegates from 20 countries and giving Zhivko Yankov, the president of the host association, the Bulgarian Ankylosing Spondylitis Patient Society, the opportunity to greet everyone and wish them a successful meeting. Seoirse then introduced the Executive Committee and welcomed everyone to ask questions of them whenever they felt during the meeting.

Acceptance of the Minutes of the previous Council Meeting.

The Minutes and Report of the 10th Council Meeting held in Izmir, Turkey, on November 17-20, 2011 were presented and, on a motion duly made, seconded and unanimously carried, approved.

President's Report – Seoirse Smith

Seoirse opened his remarks by advising, that sadly, Miloš Konrád had died recently. Miloš had long played an important role in Klub Bechtěreviků in Czechia, had many friends in ASIF and was a regular attendee of Council Meetings.

Seoirse secondly thanked the Bulgarian Ankylosing Spondylitis Patient Society for organizing this Council Meeting.

Seoirse reported along the theme “Three Years On” referring to his comments at the last Council Meeting and noting that his slides were the same as those from 2011. This is because ASIF’s priorities are the same but the challenge is in executing them.

In his report, Seoirse outlined some of the achievements of ASIF over the last few years together with the work he has done as President to involve and give visibility to ASIF.

[Click here](#) to see the slides for the President’s Report.

Treasurer’s Report – René Bräm & Seoirse Smith

The Treasurer’s Report and proposed Budget 2015 are available to Members upon request to the Secretary.

Stretch Break – led by Margaret Lewington, Physiotherapist, Australia.



Approval of New ASIF Members: Lithuania, Netherlands, Russia.

In addition to having provided information on our standard Membership Application, each of the applicants was given an opportunity to present their association in a slide show.

Lithuania

Ruta Grigiene, Chief Adviser to the Chairman of the Lithuanian Association of Patients Suffering from Bechterev Disease ‘Judesys’

(‘Movement’) presented for Lithuania. The association was formed in 2009 and has approximately 150 members. The slides outlined the objectives of the association and some of its activities, which included conferences and summer camp.



[Click here](#) to see the slides of the Lithuania presentation.

Netherlands

Danny van Krimpen presented on behalf of the Netherlands' Stichting Bechterew in Beweging (SBIB) ("Bechterew in Motion Foundation"). Leen Salij, President and Chairman of the Foundation, was also in attendance at the Council Meeting. The Foundation was formed in 2004. One of its remarkable activities is organizing an International AS Volleyball Tournament with a large number of participants from home and abroad (38 teams).



[Click here](#) to see the slides of the Netherlands' presentation.

Russia

Aleksei Sitalo, President, presented on behalf of the Ankylosing Spondylitis Patients' Association of the Russian Federation, with translation provided by Iuliia Zmeeva. The association was founded in 2012 and in the summer of 2014 held its first forum attended by about 70 patients from 14 regions in Russia.



[Click here](#) to see the slides of the Russian presentation.

On motions duly made, seconded and unanimously carried, each of the applicant associations, Lithuania, Netherlands and Russia, were approved for membership in ASIF.

Presentations: Patient Survey and Research Priorities

By Debbie Cook, Executive Director, National Ankylosing Spondylitis Society ('NASS'), United Kingdom.

Patient Survey

In the first part of her presentation Debbie gave the reasons why the survey was undertaken. Because NASS has 6,000 members, 91 branches providing physiotherapy exercises and fields 4,000 calls per year on its Help line, it feels quite well connected with patients. Despite this it wanted to be data rich to provide a better understanding of how AS patients are managed in the U.K., to campaign for better

services for people with AS and to raise awareness through media and within Parliament.



1,630 patients completed the survey, the first questions of which addressed pain and day-by-day fatigue. On a scale of 1-10 (most severe), respondents' overall AS pain was 5.41 and their fatigue almost 6. Most pain was experienced in the lower spine (80%), upper spine (74.5%), hips (44.6%) and shoulders (42.8%). Less than half of patients felt that they had received all the information they needed about their disease from their rheumatology team.

During the previous 12 months, 60% of patients had received physiotherapy. When it came to the impact of AS on working life, 53% of patients were working full or part-time, 29% were retired but 14.7% were unable to work because of their health. Over 77% of patients reported that their AS had had a negative effect on their working life.

Debbie finished this part of her presentation with key campaign messages drawn from the survey and also spoke of the Parliamentary launch of an "AS It Is" campaign and its impact to date.

[Click here](#) to see the slides of the presentation on the NASS AS Patient Survey.

Research Priorities in Ankylosing Spondylitis

In the second part of her presentation, Debbie provided findings taken from 150 responses from NASS members when asked about research priorities. The findings were reviewed and elaborated on at a workshop held at Lancaster University, then formulated into a

survey. The workshop generated 39 research priorities which were divided into five categories; managing your AS, psychological health and wellbeing; lifestyle; medical/clinical management of AS and exercise, activity and sport.

Respondents were asked to rate priorities on a scale of 1-5 (most important) and then asked which one priority in a category they would like to see developed. Finally, they were asked which of the five categories they would most like to see researched.

There were 711 people who responded to the survey, of which 95 were patients with AS, 3% were a friend or family member of someone with AS and 2% were health professionals. Managing your AS (39%) and Medical Management of your AS (33%) were the top two categories that respondents most liked to see researched.

A top five research priorities were developed from the survey. These were: develop a greater understanding of AS triggers that lead to flares; evaluate different ways of improving GP/HCP (General Practitioner or Doctor and Health Care Provider) understanding of AS; develop better understanding of the impact of fatigue on people with AS; provide better understanding of the type of exercise needed depending on age and severity, and develop a self-management program to help people manage their AS effectively.

Debbie finished her presentation by outlining what actions and progress are being made in respect of the research priorities.

[Click here](#) to see the slides of the presentation on Research Priorities in Ankylosing Spondylitis.

Press Conference

The host association arranged a press conference that was recorded for media use. Seoirse introduced himself as President of the Irish AS Association and President of ASIF. He addressed some of the history of ASIF, its aims and objectives, operations and partnerships.

[Click here](#) to see the video of the Press Conference. (Day 1, Part 7 10:00 to end; Part 8 00:00 to 5:00)

Workshop Pre-Discussion

Seoirse and Hedley Hamilton outlined the purpose of the workshops in light of ASIF's strategic plan and how the workshop topics can help determine the plan for the next few years.

Workshops

Delegates were divided into four groups in different parts of the room for the four workshop topics. Every 30 minutes the facilitator for each workshop moved to the next group so that over the course of the afternoon each group had discussed each topic.

The topics were:

1. What is the role of ASIF; how do we grow it and make it more relevant?
2. Regional Councils
3. How do we brand 'AS' and promote World AS Day?
4. Biosimilars: What patients should know.

The findings of Workshops 1 and 3 will be subject to further discussion by the Executive Committee and incorporation in the ASIF Strategic Plan.

In regard to Regional Councils of ASIF, some felt that these made sense to build the AS community and assist them with their own associations, but the overall feelings was that it is better to have a single forum - our council meetings – where topics of common interest can be discussed and dealt with.

The findings of the Biosimilars workshop were that there is the need for more information about both biologics and biosimilars and the regulatory environment. This is something that ASIF should move forward on to provide information for its members.

Exercise and coffee break sessions were held during the afternoon.

Saturday, November 8, 2014

ASIF Executive Committee Elections.

Elections for the Executive Committee were held. In view of the resignations of Debbie Cook and René Bräm, whom we thank for their services, there were three positions to be filled because there already was one open position.

Standing for re-election until the next Council Meeting were:

Seoirse Smith (President, Ireland)

Hedley Hamilton (Vice-President, United Kingdom)

Michael Mallinson (Secretary, Canada)

Dr. Tuncay Duruöz (Turkey)

Nominations to fill the vacant positions had been solicited prior to the Council Meeting and from the floor. Those standing for election until the next Council Meeting were:

Ruta Grigiene (Lithuania)

Raj Mahapatra (United Kingdom)

Andri Phoka (Cyprus)

Zhivko Yankov (Bulgaria)

The nominees for the vacant positions were invited to speak for a minute or two to introduce themselves to delegates. However, Andri Phoka was not present at the meeting.

On motions duly proposed, seconded and unanimously carried, all nominations of those standing for re-election were approved. Likewise, on motions duly proposed, seconded and unanimously carried, the following were elected to the Executive Committee: Ruta Grigiene, Raj Mahapatra and Zhivko Yankov.

It is noted that the position of Treasurer remained unfilled after this election. The Executive Committee will conduct a search for a suitable candidate to appoint until the next Council Meeting.



The new Executive Committee. From left to right: Dr. Tuncay Duruöz (Turkey), Zhivko Yankov (Bulgaria) , Raj Mahapatra (United Kingdom), Ruta Grigiene (Lithuania), Seoirse Smith (Ireland), Michael Mallinson (Canada), Hedley Hamilton (United Kingdom)

Presentation: Biosimilars in rheumatic disorders: the science behind them and their place in clinical practice.

By Prof. Peter Taylor, MA, BM, BCh, PhD FRCP, Norman Collisson Chair of Musculoskeletal Science at the University of Oxford, based within the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences.



Prof. Taylor gave a very interesting talk on biosimilars. Unfortunately, Prof. Taylor has advised that because the field has since moved on with dozens of biosimilars in development and that there are contentious areas regarding interrelation of adverse events seen in trials, he would prefer not to give permission for us to show the video of his presentation. Instead a written report will be provided at a later date.

Prof. Taylor's presentation was followed by a coffee and exercise break. Many delegates noted that these breaks were a good networking opportunity and consideration should be given in future Council Meetings to more networking time.

Presentation: NASS, ASIF and Social Media, by Debbie Cook, Executive Director, NASS.

Debbie talked mainly about Twitter on the understanding that most people know about Facebook. Once she became Executive Director of NASS, Debbie started engaging people through social media, because everyone, young and old, is using it. With social media you can reach out, engage and connect quickly. Debbie demonstrated this by the fact that she has been using Twitter to direct people to the NASS website. Website visits have increased dramatically in the last three years.

Debbie instructed us on how to use Twitter by setting up an account, following others, re-tweeting and using hashtags (#).

Debbie established a Twitter account for us: '@ASIntFed'. Please follow us.

ASIF also opened a Facebook site 'ASIF-Ankylosing Spondylitis International Federation'. Please 'Like' us.

[Click here](#) to see the slides of the presentation on Social Media.

Proposed dates and venues of the next Council Meeting.

Seoirse opened the discussion of where and when to have the next Council Meeting and asked if any members were interested in hosting. The Russian Association expressed an interest in hosting in either Moscow or St. Petersburg. It will be provided with the guidelines for hosting.

Closing Comments.

In closing the Council Meeting, Seoirse thanked Zhivko and the Bulgarian AS Patients' Society for hosting and expressed the hope that all delegates would take away something positive from the meeting.

Zhivko, in accepting the thanks, said that he had enjoyed the planning of the meeting, that it had been fun to do it and urged other members to consider hosting next time. He also said on behalf of the Bulgarian AS Patients' Society, it had been good to welcome and meet AS patients from other countries. This brought an end to the formal proceedings of the 11th ASIF Council Meeting.

Social Program: Visit to the Rila Monastery.

Following lunch and a group photo, all the delegates boarded a bus for one of Bulgaria's most visited sites, that of the Rila Monastery, some 120 kilometers south of Sofia. The bus ride there gave delegates an opportunity to see some of the Bulgarian countryside, towns and villages. The monastery itself is located in the valley of the Rilska River in the Rila Mountains. Delegates were treated to wonderful scenery on the road up the valley.

The guides provided by the host Bulgarian Ankylosing Spondylitis Patient Association proved knowledgeable and entertaining as they described the history and features of this beautiful monastery. You

may read more about the monastery here:
https://en.wikipedia.org/wiki/Rila_Monastery



The Rila Monastery

Social Program: Dinner

Following the delegates return to Sofia, everyone was given a short time to freshen up before leaving for a dinner at a popular restaurant, the Watermill, where they were joined by local members of the Bulgarian AS Patient Society and were entertained to traditional food and a fire-walking dance!



For more pictures of the Council Meeting, [click here](#).