



Ankylosing Spondylitis International Federation

World-wide network of societies of patients suffering from ankylosing spondylitis or related diseases

MINUTES OF THE 10TH ASIF COUNCIL MEETING THURSDAY NOVEMBER 17TH TO SUNDAY NOVEMBER 20, 2011 BALÇOVA THERMAL HOTEL, IZMIR TURKEY

Delegates and guests were greeted upon arrival at the hotel on Thursday November 17th by members of the ASHAD welcome committee and were presented with a gift package and an invitation to attend a welcome reception that evening. Prof. Dr. Tuncay Duruöz, President of ASHAD welcomed everyone and wished all delegates a very successful 10th ASIF Council meeting in Izmir. Prof Ahmet Mete Işıkara, honorary member of ASHAD, also welcomed ASIF delegates to his beautiful country and spoke briefly of his work for AS patients in Turkey. Turabi Galebi, General Manager of the Balçova Thermal Hotel was pleased to welcome ASIF delegates and extended the hospitality of his hotel and staff. Delegates and guests then enjoyed a lively folk music presentation with musicians and dancers while enjoying the reception and dinner.

Friday October 16

Delegates and guests from 13 countries including Australia, Austria, Canada, China, Czech Republic, Denmark, Germany, Ireland, the Netherlands, Norway as well as Switzerland, Turkey and the United Kingdom attended the 10th Ankylosing Spondylitis International Federation Council. Delegates introduced themselves and gave a brief description of their role in their home society. The list of delegates is enclosed (Appendix I).

Seoirse Smith, ASIF president (Ireland), thanked Prof. Dr. Tuncay Duruöz, president of the Turkish AS society and the members of the organizing committee for the splendid organization of the 10th ASIF Council meeting and the warm welcome and dinner reception the prior evening. Seoirse also thanked the General Manager of the Balçova Thermal Hotel, the distinguished speakers and entertainers who welcomed the ASIF delegates and guests. A special welcome was extended to the Chinese delegation for attending their first ASIF Council meeting.

Seoirse called the meeting to order at 9:18 A.M.

Acceptance of the Minutes of the previous Council Meeting

The Minutes of the 9th ASIF Council meeting held on October 16-17, 2009, at Bad Hofgastein, Austria, were accepted as presented.

1. President's report – Seoirse Smith

Seoirse outlined some of the accomplishments of ASIF over the last 2 years.

Communications

The executive committee now meets more frequently, using internet technology to have virtual meetings and thereby avoid the need for expensive travel. We are continuing to develop important PARE / EULAR connections, with thanks to Jane Skerrett and particularly, Cor van Drogen, as he continues to play a key role. Connections have been made with similar organizations IFPA and EFCCA. ASIF had a very successful booth at the EULAR conference in

Executive Committee: Seoirse Smith (Ireland), President; Hedley Hamilton (U.K), Vice President; Michael Mallinson (Canada), Secretary; René Bräm (Switzerland), Treasurer; **Additional members:** Debbie Cook (U.K.); Cor van Drogen (Netherlands), Prof. Dr. Tuncay Duruöz (Turkey); **Scientific Advisor:** Prof. Dr. Ernst Feldtkeller (Germany)

London in May 2011 which was staffed by the people at NASS. Prof. Dr. Ernst Feldtkeller, in his role as the ASIF scientific adviser, continues to engage with medical professionals and scientific studies. World AS day gathers momentum with more member organizations holding events in early May.

WEB Based Tools

ASIF has engaged some of the leading pharmaceutical companies. Pfizer (formerly Wyeth), at a European level, is helping to produce an international awareness campaign called Back-In-Play, an internet game, which has been launched in a number of countries. ASIF is also working with Abbott International on ASleep, an internet-based Rheumatic-friendly room finder tool for people with AS who are traveling. Seirse also mentioned he has attended European and International meetings recently with Abbott to raise the awareness of patient organizations at the pharmaceutical level. There are, however, challenges ahead for ASIF as it continues to develop the ASleep program, the ASIF website and alternate methods of communication with members.

3. Treasurer's report - Torben Jørgensen

Torben presented the actual audited 2009 and 2010 ASIF accounts in Euro dollars.

Highlights	2009 (Euros)*	2010 (Euros)*	Annual Budget 2010/2011 (Euros)
January 01 holdings	21,513.57	22,523.11	
Income	10,174.47	90,679.00	74,500
Expenditures	9,164.93	16,983.49	80,800
Results of the Year	1,009.54	73,695.51	-6,300
December 31 holdings	22,523.11	96,218.62	

* 2009-2010 financial statements audited by René Bräm, Switzerland

Comments

Torben – Sponsorships covered some ASIF executive members meeting in EULAR 2009 – 5910 Euros, EULAR 2010 – 8723 Euros. Torben advised that Abbott has provided sponsorship in 2010 in the amount of 70,000 Euros for the development of the ASleep project.

Seirse advised that resourcing project contractors allowed for some favourable savings and that any monies not spent must be returned to Abbott.

A motion to approve the financial statements was passed unanimously.

4. Approval of new society memberships

There were 3 applications submitted from 3 patient societies for membership to ASIF. All had provided the necessary forms in advance to the ASIF secretary.

a) Association of Chinese AS Patients and Medical Advisory – attending from the new AS patient organisation in China which was founded in 2011, were rheumatologist and AS patient Dr. Zhiming Lin, and rheumatologist and president of the new society, Dr. Jieruo Gu. Dr. Gu gave a brief presentation and expressed the wish that their organization will continue to grow and contribute to the well being of AS patients in China.

b) Cyprus League Against Rheumatism – we received messages from Persefoni Markidou, Psychosocial Support Officer and from Andri Phoka, General Secretary of CYPLAR, expressing regret that they were unable to attend and that the AS group within CYPLAR aims to inform members of the association with AS and generally the public about the disease. The group celebrated the World Day of Ankylosing Spondylitis on 7th of May 2011 with a hydrotherapy workshop, which involved only people with Ankylosing Spondylitis.

c) Korean Organization of Ankylosing Spondylitis – we received a message from Seung-ho Lee, chairperson of KOAS that due to his extremely busy schedule he was not able to attend this year but hopes to meet us all at the next ASIF meeting. KOAS was founded in 1988 and he mentioned that we will work together to enhance disease awareness in the future.

After a brief discussion all 3 applications were approved by the delegates. This brings to 35 the number of patient societies that have joined ASIF since the inaugural meeting in Bath U.K. in 1988.

5. 1st ASIF Council meeting July 1989 – Ken Mulholland

Ken presented a brief video showing delegates and guests attending the meeting in the scenic alpine village of Leukerbad, Switzerland. The video highlighted excerpts from the meeting along with a tour of the clinic and an excursion to Zermatt and the Gornergrat.

6. Approved New Therapies in Ankylosing Spondylitis - Prof. Dr. Tuncay Duruöz

Prof. Duruöz presented an overview of the disease followed by a very interesting report on the various tools used to diagnose the disease along with the many recent treatment options that are considered by the physician.

7. ASIF Website – Seirse Smith, Hedley Hamilton

In conjunction with the development of the ASleep program, the developers are looking at a redesign of the ASIF website. Seirse and Hedley are also looking at various options and brand organisations to develop a new, fresh ASIF brand logo.

Lunch

Break for lunch and a tour of the Spa facilities at the Balçova Thermal Spa Hotel. After lunch delegates were treated to an escorted tour of the large facility which treats approximately 5,000 patients annually with a large number of rheumatic patients attending from Norway. It offers a wide range of health and tourism services including physical therapy, rehabilitation and thermal spring treatments.

8. Looking Ahead - Prof. Dr. Paul Wordsworth, University of Oxford (U.K.)

Dr. Wordsworth discussed the case of a patient who first noticed back pain at age 25. For the next 25 years this patient went through a series of misdiagnosis and treatments including surgery before he was finally properly diagnosed and treated with Aniti-TNF medications. NASS has produced an excellent booklet ``Looking Ahead`` which describes in detail the current best practices for treating patients with AS. The older criteria for diagnosis have been replaced with more recent criteria that can better distinguish between inflammatory from mechanical back pain.

9. Influencing patient management– Debbie Cook, Director, NASS (UK)

Debbie presented a compelling set of guidelines that patient organizations can use to influence the decision makers as NASS has done successfully in the U.K. Patient organizations need to document their case by providing as much information as possible on how the programs of the patient associations are saving their National Health Plans. They then need to meet with the appropriate politicians who can influence health care, by using social media (Facebook, Twitter), to show strength of support that the patient organisations offer to their members through patient education, seminars, support groups, physiotherapy and statistics where available (clinical study data). Websites also need to be updated on a regular basis, daily if possible.

10. The benefits of cardiovascular training in patients with AS

Reto Baliarda, ASIF webmaster, (Switzerland), presented the results of a randomized control study that the SWISS AS society participated in. The study tested the effect of cardiovascular training with 2 groups, a Nordic Walking Training Group and a Coping Control Group. 106 AS patients enrolled in these state-of-the-art spinal mobility classes. The study took into account age, sex, BMI, smoking status, baseline physical activity, perceived disease activity (BASDAI), TNF alpha treatments and baseline fitness. 85% of the exercise group trained at least once a week and 75% trained 3 times a week over a period of 12 weeks. The control group met once a month for 2 hours over the 12 weeks and their coping progress was monitored. Each participant kept a diary.

The conclusions were that cardiovascular training is useful in addition to mobility exercises in AS patients, improving their fitness, which may lead to further health benefits. Nordic Walking is feasible for people with AS. All endurance sports are feasible, but visit your rheumatologist beforehand. This study which included 10 training recommendations won a prestigious award at the EULAR Conference in 2011 over 3,500 abstracts submitted.

11. Genetics of Ankylosing Spondylitis & the development of new treatments

Prof. Dr. Paul Wordsworth, University of Oxford (U.K.), explained why researchers study genetics of AS. Curiosity plays a role as they look for clues to a faster diagnosis, improved prognosis, new treatments and ultimately a cure. In a study in 1973 of AS patients it was discovered that 72 out of 75 patients tested HLA-B27 positive. Since 1973 much progress has taken place in the study of genetics including the discovery of the ERAP1 gene which has been found to influence the risk of AS. He further described the exciting possibilities of the research being conducted in 3 research centers. They are Oxford U.K. under Paul Wordsworth, Houston Texas under John Revielle, and Brisbane Australia under Matt Brown. There are 15,000 patients world wide in this study including a very large group of NASS patients. It is hoped that this extensive project will play an important role in the development of new treatments for AS. There is the potential for ASIF to participate in future research.

12. Instructions given to patients with ankylosing spondylitis by their diagnosing doctors

Prof. Dr. Ernst Feldtkeller, ASIF Scientific Advisor (Germany), discussed a DVMB patient survey presented at the International Congress on Spondyloarthropathies 2010 in Gent (Belgium). The objective was to evaluate what information patients with AS had received from their diagnosing doctor and to compare this with what they later felt was most valuable. The questionnaire, consisting of 82 questions was sent to 3400 randomly selected members of DVMB.

Conclusion: Most patients were informed in connection with their diagnosis only about medical therapies and not about how they, themselves, may contribute to a favourable disease outcome. Doctors making a diagnosis of AS, should not forget to inform their patients about the patient's own possibilities to contribute to a favourable course of the disease.

13. The Changing Profile of Exercise Group vs. Individual

Claire Harris, Physiotherapy Advisor to NASS (UK), presented evidence from the Cochrane Review of Physiotherapy interventions for AS that exercise programs, home-based or supervised, are better than no exercises and improve movement and physical function. Group exercises are better than home exercises, and improve movement and overall well-being. Claire outlined both the good and bad aspects of group exercise however the one thing that can be missing in individual exercise is education. NASS has an abundance of reference materials that are available to their members and support groups. One of the latest is the "back to Action App" which is available for download from their website.

14. Proposal of a new ASAS project

Prof. Feldtkeller presented a new ASAS project on appropriate patient behaviour and environmental adaptations. It is a list (a core set) of information which a patient with AS should receive, either in connection with the diagnosis, or thereafter, as well as in patient education programs. This core set should be made available to rheumatologists, other physicians and health care providers, who may diagnose, treat and educate patients with the disease. Patient organizations, rheumatologists will participate and results will be evaluated and eventually published.

The afternoon concluded with the delegates and guests allowed some free time to participate in the many activities offered at the Balçova Thermal Hotel and Spa. The day concluded with a typical Turkish dinner and social evening.

Saturday November 19

Seoirse called the meeting to order at 9:20 A.M.

15. ASIF Executive Committee Elections

Torben Jørgensen was unanimously approved to chair the election.

Ken Mulholland Canada, Torben Jørgensen Denmark are stepping down from the executive at this meeting. Jane Skerrett U.K. had previously resigned earlier in the year.

Nominations submitted for four executive committee officer positions.

President: Seoirse Smith, Ireland

Vice President: Hedley Hamilton, United Kingdom

Secretary: Michael Mallinson, Canada

Treasurer: René Bräm, Switzerland

There being no further nominations the four officer positions were acclaimed.

Nominations submitted for three additional committee positions.

Cor van Drogen, Netherlands

Tuncay Duruöz, Turkey

Coby Otter, Belgium/Flanders

Debbie Cook, United Kingdom

A vote then took place resulting in Cor, Tuncay and Debbie being elected.

Seoirse thanked Ken and Torben for their hard work and service over the years and presented them with a lovely gift from Turkey to remember the occasion.

16. The ASleep Programme

Seoirse Smith presented an exciting new initiative in which ASIF is partnering with Abbott International. ASleep is an internet-based Rheumatic-friendly room finder tool for AS people who are traveling. The idea behind ASleep is patient-driven and from the Danish AS patients' request for information and that organization's knowledge of a similar program for Crohn's & Colitis patients. A survey in multiple languages was initiated last year with AS patients and the results indicated a real need for this service while traveling. A hook or tag will appear in many places and makes the direct connection to hotel rooms, undisturbed sleep and has "AS" featured prominently. The project is expected to be rolled out in 3 European countries in 2012 and then expanded to other countries. There will be possibilities for AS patient groups in each country to participate in the project and to help identify participating hotels. As part of the development of this project the ASIF website.

Questions:

Q - Who determines what is a “patient friendly” bed? **A** - Asleep will only mention that the hotel offers a choice.

Q - What impact on Local AS Society? **A** – Very minimal, may help identify the hotels.

Comments:

Patients other than those with AS would benefit from this project. For example, patients with mechanical back pain. There will be exciting possibilities for all countries that will be involved.

The delegates applauded the efforts of Seirse Smith, Hedley Hamilton, Jane Skerrett and Debbie Cook for all the work that they have put in on this exciting project over the last year to bring it to this point.

17. Norwegian Spa Program

Liv Sviland, ASIF delegate (Norway) explained the program that allows Norwegian AS patients to attend a 4 week treatment session at a Spa facility out of country every 2 years. This is due to that fact that there are not enough suitable facilities in Norway. The Balçova Thermal Hotel in Turkey is one of the approved facilities that Norwegian patients can attend as part of the treatment program. Montenegro is also another approved location. The program is covered, if the patient qualifies, and is paid by the national tax-funded health care program. Liv, and fellow delegate from Norway, Jon Hagfors have participated several times in this program.

18. Proposed date and venue of the next ASIF Council Meetings in 2013 and 2015

There were no submissions for the next meeting. It was noted that the following submissions were offered at the 2009 ASIF Council meeting in Austria.

a) Belgium/Flanders – 2013

c) France – 2013/2015

The ASIF executive will contact these societies to follow up.

Ernst Feltkeller mentioned the Austrian Society would agree again to host the next meeting should no other society come forward.

19. Other ASIF business

Changes for ASIF – Seirse asked the delegates to consider the projects currently underway in ASIF. What is ASIF now and what can we do better?

Research – share research results, multinational coordination, consider a volunteer coordinator.

Tools – use all the diagnosis tools available.

Pro Active – ASIF needs to be more pro active. One way to do this would be to hire a paid director. That question was put to the delegates. The delegates unanimously approved. The executive will consider this option.

Seirse and Tuncay gave closing comments and the business portion of the meeting was adjourned at 12:15

The ASIF meeting concluded on Saturday at noon to allow the delegates and guests time to participate in a special overnight excursion to these nearby historical locations of Ephesus, Pamukkale and the UMUT Thermal Hotel Clinic & Spa. This special excursion was arranged by Tuncay Duruöz, president of the Turkish AS society and the members of the organizing committee. The 10th ASIF Council meeting concluded on Sunday morning with the delegates and guests returned to Izmir to complete their travel arrangements home.

At the minutes,



Ken Mulholland, ASIF Past Secretary

Agenda for the 10th ASIF Council Meeting

APPENDIX I

ASIF Delegates and Guests attending in Turkey, Nov 17- 20, 2011

Country	Name		Position in Home Society
TURKEY	DR TUNCAY DURUÖZ	D	President
TURKEY	DR. SALIH OZGOCMEN	D	AS representative
TURKEY	ÜLKÜ UÇAR	O	Organizing Committee
Australia	Mrs. Margaret LEWINGTON	D	Physiotherapist
Austria	PAUL POCEK	D	President
Austria	RUTH KURZ	D	Journal Editor
Canada	MICHAEL MALLINSON	D	President
Canada	KEN MULHOLLAND	D	Treasurer
China	DR. JERUO GU		President
China	DR. ZHIMING LIN		AS representative
Czech Republic	DR. MILOŠ KONRÁD	D	Board member
Czech Republic	JARMOIR FAJKUS	D	Vice-chairman
Denmark	Torben JØRGENSEN	D	Web Editor
Denmark	WILLY J. FLICK	D	AS representative
Germany	PROF. DR. ERNST FELDTKELLER	D	International contact, journal co-editor
Germany	ECKHARD PFEIFFER	G	Journal co-editor
Ireland	SEOIRSE SMITH	D	Secretary
Netherlands	COR VAN DROGEN	D	AS representative
Norway	JON HAGFORS	D	AS representative
Norway	LIV MARGO SVILAND	D	AS representative
Switzerland	RETO BALIARDA,	D	AS representative
Switzerland	KARIN WERNER	D	AS representative
U.K.	DEBBIE COOK	D	Director
U.K.	HEDLEY HAMILTON	D	Chairman
U.K.	CLAIRE HARRIS	G	Physiotherapy Advisor
U.K.	DR. PAUL WORDSWORTH	G	Prof. University of Oxford

Code : D = Delegate, A = Accompanying Person, O = Host Country Organizing Committee, G = Guest