

**Minutes of EUTi Meeting,
held at the Lufthansa Building, Munich Airport,
on 19 January 2011, 12.00 – 16.00 hrs**

Members and guests present:

Volker Albert, Germany (DTL is a member, invoice is enclosed)
Jan Anjou, Great Britain
Dr. Eberhard Biesinger, Germany
Martin Carroll, Ireland (for application for membership please use enclosed form)
Léon Delobbe, Belgium (ASBL)
Yolande Delobbe, Belgium (ASBL is a member, invoice is enclosed)
Isabel Diges, Spain (for application for membership please use enclosed form)
Sylvia Dorner-Mitschke, Germany (TRI, as a guest)
Prof. Gerhard Goebel, Germany (DTL is a member, invoice is enclosed)
Dr. Manfred Koller, Austria (ÖTL is a member, invoice is enclosed)
Frode Larson, Denmark (for application for membership please use enclosed form)
Dr. Paola Perin, Italy (for application for membership please use enclosed form)
Dr. Andreas Schapowal, Switzerland (STL is a member, invoice is enclosed)
Conrad Schätz, Germany (Web Administrator, as a guest)
Dr. Loes Schenk-Sandbergen, Netherlands (NVVS is a member, invoice is enclosed)
Kirsten Volmer Worsoe, Denmark (as a guest)
Karen Munk, Denmark (as a guest)

The meeting of the members is opened at noon by EUTi President Dr. Eberhard Biesinger, who states that the invitations to this meeting were sent out in accordance with the statutes and in due time. He presides the general meeting as its Chairman. It is noted that representatives of five tinnitus organizations with a right to vote are in attendance at the Munich meeting. Pursuant to Article 9 (2) of the Statutes the meeting is thus quorate.

The Chairman asks participants whether they agree that guests are admitted to the meeting. No objections are raised.

Report of the President

Dr. Biesinger gives a short overview of EUTi activities and developments in 2010.

A minute of silence is observed in memory of the deceased Carlos Herraiz, who lost his life in a tragic accident in spring 2010.

There is nothing special to be reported as regards the year 2010. EUTi's homepage is visited regularly and more and more often. Other organizations seek cooperation with EUTi and use the potential of its site to advertise for events, for example a congress. Dr. Biesinger emphasizes that activities within EUTi must come from the

members, whereas he sees his task as President mainly in maintaining the communication structure and helping to keep the communication among members going.

Participants are requested to check whether their entries on the EUTi homepage are still up to date. It is also suggested that they use the site to inform about upcoming activities, events, etc. Promotion ads are financially supported by EUTi. The costs should, however, be made known to the Board in advance. Any request for changes should be addressed to the Chairman. Finally, the President once again encourages participation in the International Tinnitus Congress to be held in Brazil in March and urges members to make use of the possibility of public viewing via internet available at moderate cost.

Reports of the individual national representatives

Excused are:

Hungary: Due to illness it was not possible to send a representative. The report received by e-mail reads as follows:

“We would like to welcome the member organizations of EUTi. We sincerely regret that we couldn’t join the conference in person. Hopefully we will be able to do so in the future. Some data about the Hungarian Tinnitus Association: It was founded on 15 July 2000 in the MÁV Hospital. The founders were specialists (otolaryngologists, psychologists, psychiatrists, neurologists, physicians) as well as patients suffering from tinnitus. We have received support for the foundation from the German Tinnitus League (DTL). During the last 10 years we have grown to 1100 members (including supporting members). We have joined EUTi in 2002.

Chairman: Dr. László Szalai (psychologist)

Vice Chairman: Dr. Tibor Várkonyi (lawyer)

Secretary: Zoltánné Kiss

Consultants: Dr. Zsuzsanna Ferenczi (otolaryngologist), Dr. Attila Márkus (Ph.D., neurologist and psychiatrist), Dr. Ilona Hári (psychologist).

Our activities are:

- Contact with the Association of Hungarian Otolaryngologists. Train 4-5 doctors each year in TRT therapy,
- Operate an information (phone) line. Website: www.tinnitus.hu - will be updated soon with more attractive design and content,
- Yearly tinnitus newspaper for members,
- Organization of club afternoons, supporting groups,
- Opening of two tinnitus centers so far,
- Publication of two books about tinnitus so far,
- Maintain international relationships with other member organizations of EUTi, especially the German and French organizations. “

France: Excused.

Austria: Dr. Manfred Koller reports on the activities of the Austrian Tinnitus League (ÖTL) in the year 2010:

“ ÖTL was founded in 1998 by tinnitus sufferers and is largely sustained by the activities of its self-help groups in all of the nine Austrian provinces. At present, there are 16 groups which meet once or twice a month. Depending on the commitment and activity of their group leaders they function more or less well.

We regard our self-help groups as relay stations providing genuine human understanding for many tinnitus sufferers who have been in search of relief for a long time. Moreover, we do our best to spread impartial information by lectures and speeches given in the self-help groups, without any ulterior commercial motive. Our website www.tinnitus.at is visited by many people and may be used free of charge.

For persons, who do not live anywhere near a self-help group or do not want to join a group, our members' journal 'ÖTL-Tinnigramm' proves helpful. It is published four times a year, and I do the editing and designing myself. Print runs range from 2500 to 3000 copies. The journal contains scientific articles, news from the self-help groups as well as a calendar of events and useful addresses. The 50th issue of the *Tinnigramm* will be published on 1 April 2011. A huge amount of work which I practically do single-handedly and on a voluntary basis. Printing and mailing of the *Tinnigramm*, which also goes to many relevant institutions free of charge, account for the major part (two-thirds) of ÖTL's expenses.

At present, ÖTL has 1150 members. That is a drop in number when compared to the 1900 members we once had – the reason being deaths, withdrawals and the loss of valid addresses (many do not notify us of a change of address). Unfortunately, the payment behaviour of members leaves a lot to be desired. ÖTL is no better off than other Austrian associations: scarcely more than 50% of the members pay their membership fee of € 25.

Since public subsidies will continue to decrease in 2011, we must calculate tightly and save money. And this despite the fact that all persons working for ÖTL are volunteers and do not get any pay. That goes for me as well.

In 2010 it became necessary to have the new tinnitus info folder reprinted due to high demand. We subsequently provided all ENT physicians and ENT clinics in Austria with a fair amount of copies requesting that the folders be displayed in medical practices or handed over to tinnitus sufferers. Apart from raising awareness in the monthly meetings of the self-help groups, ÖTL also does PR work in the media with the result that several qualified reports about ÖTL have appeared.”

Dr. Koller urges participants not to lose sight of the target group, namely the tinnitus sufferers. EUTi is a self-help organization of tinnitus sufferers, not of physicians. The President expressly endorses this statement suggesting that projects be initiated which benefit the flow of information – especially via internet – and thus benefit sufferers in all of Europe.

As a **guest** without any ties to a tinnitus self-help organization, Jan Anjou, long-time President of the Swedish tinnitus association now living in London, reports that intensive research work is being done in a number of Swedish universities. There is no coherent self-help group in Sweden. His attempts to get in touch with the British tinnitus association have so far been frustrating. He will remain open to EUTI's activities and support them as good he can.

Switzerland: Dr. Andreas Schapowal reports that the Swiss Tinnitus League (STL) has meanwhile 350 members . Publications appear in the German *Tinnitus-Forum* for the German speaking region. Meetings are organized twice a year. It is to be deplored that ENT physicians show no interest in tinnitus. The STL homepage recommends no more than 12 specialists in otolaryngology and psychology. There are two tinnitus out-patient departments at the clinics in Bern and Basel, but no longer in other university towns. The Swiss Tinnitus League came into the focus of attention when in 2010 a well-known person got tinnitus and STL was repeatedly mentioned in the media in this context.

Spain: Isabel Diges says that the year 2010 was overshadowed by the death of Carlos Herraiz. She attempts to set up a *Carlos-Herraiz-Foundation* in his memory. The foundation is intended to promote work regarding prevention, science and also self-help activities. Diverse specialist societies in the fields of medicine and industry engage in this project. Access to this foundation shall be on an international level. There is a second tinnitus self-help group operating locally in the Barcelona area. Unfortunately, no cooperation exists between Madrid and Barcelona.

Denmark is represented by Frode Larson, Kirsten Worsoe and Karen Monk. Frode Larson represents the tinnitus group which forms part of the hard of hearing organization. His task is to distribute information material and organize meetings. In 2010 two meetings took place which were attended by more than 100 tinnitus sufferers. In addition to spreading information and organizing further training, treatment options are offered to tinnitus sufferers in so-called communication centers. The '*House of Hearing*' in Copenhagen is such a center where the two ladies present here assist in the care of patients. Anybody suffering from tinnitus may go there and will be cared for after a waiting time of only two weeks. Specific therapies on a case-by-case basis, counselling and relaxation techniques are offered. Initial and follow-up training of therapists was largely carried out by Prof. Hesse in Arolsen. The Danish tinnitus group will try to establish contact with Norway.

Belgium is represented by Mr. and Mrs. Delobbe. The Belgian tinnitus self-help group is mainly active in the French speaking part of the country, but has also good contacts with the Flemish part. Five meetings were organized in 2010. The Belgian tinnitus league was founded 12 years ago and has presently 300 members. It does not get any public subsidies, but is being supported by the ENT specialist society. Member fee is € 28.

The focus of work is on the following three aspects:

1. Raising awareness: Information of tinnitus sufferers, society, politicians and the Ministry of Health. Appearances in schools and also at concerts to raise

awareness. Distribution of ear plugs, information material and a booklet on noise-induced hearing impairment at concerts. In 2010 active participation in the '*Week of Health*' held in Liège, where Mr. and Mrs. Delobbe gave a presentation on tinnitus as part of the main topic on hearing.

2. Information: Information is provided via the website, through booklets and the organization of meetings (five in 2010). Close contact is kept with French scientists, physicians and psychologists.
3. Support: Support of the local tinnitus self-help groups which are spread all over Belgium (by organizing meetings). Mrs. Delobbe is actively engaged in a hotline.

Italy: Dr. Paola Perin reports that in 2010 the Italian self-help organization was engaged in raising awareness of politicians and society concerning tinnitus. This proved especially successful in the region of Friaul, where a well-known person suffers from tinnitus. In Italy, there is a veritable jungle of information about tinnitus. The information provided shows a lack of structure and does not necessarily reflect current scientific knowledge. It is a pleasing development that several universities (e.g. Padua) under new management open up to tinnitus and increasingly make moves towards tinnitus sufferers. It is now imperative to look for committed physicians in towns and communities to support persons in need and organize proper diagnostics and therapy.

Netherlands: Dr. Loes Schenk-Sandbergen reports that self-help in the Netherlands is organized in the Tinnitus Commission, a subdivision of the Hard of Hearing Organization founded in 1986. The subdivision consists of 7 active members who are responsible for different tasks which they perform in the local groups within the self-help structure of the Hard of Hearing Organization. Information evenings take place monthly. It is difficult to recruit new members, although the annual membership fee is only € 25.

The commitment consists in participating in conferences, distributing information material and making available a very nice noise CD. The hotline of the tinnitus self-help organization is supported by the state and also by ENT physicians. A web forum exists which is, however, not very well structured. Efforts are made to support tinnitus sufferers with legal problems and to raise awareness among students. A newsletter is published and an annual meeting is held.

The tinnitus clinic in Hoensbroek, Netherlands, is no longer supported by the state, evidently because there was no sufficient documentation on the effectiveness of treatments. Reviews accepted by the Dutch Government and/or the Ministry of Health must be submitted in the English language. The tinnitus group fights for the extension and maintenance of the tinnitus clinic so as to save treatment places for tinnitus patients there.

Another strong commitment is the support given to the victims of traumatized patients and to soldiers having served in Afghanistan.

Ireland is represented for the first time by Martin Carroll. The self-help organization has been in existence for three years and counts 300 members. All work is done on a voluntary basis. Self-help is organized in 6 active support groups which meet approx. once a month. Topics discussed there and knowledge imparted range from relaxation methods to general support. Efforts go into making the public more aware of tinnitus. A hotline exists which is operated twice a week. A well-known radio journalist gives helpful support. A bulletin is published on a regular basis. Formal communication exists with the British Tinnitus Association and the German Tinnitus League.

Germany: Volker Albert reports on the diverse activities of the DTL. Something new is the active voting membership in the International Federation of Hard of Hearing People (IFHOH) whose European self-help organization (EFHOH) will hold an international congress in Vienna in April 2011. This will enable DTL to operate from a broader basis, also with regard to scientific activities and the mutual support between the hard of hearing organizations. The German Tinnitus League has been in existence for 25 years now, and there will be an international congress in Bonn on 01-02 July 2011 to celebrate this anniversary. Further efforts will be directed towards establishing and maintaining more political connections as well as structuring and intensifying the training of group leaders.

The Tinnitus Research Initiative is represented by Sylvia Dorner-Mitschke who reports that TRI, Regensburg, which formerly depended on private sponsoring has now been transformed into a foundation. Efforts are made to collect endowment funds intended to be allocated for research. The will to also support EUTi is certainly there, but this can only be done, if and when sufficient money is available.

Report of the Treasurer:

Income and expenditure see Annex.

The Treasurer, Volker Albert, urges once again that the member countries pay their modest fees. If not, there is a risk that the status of non-profit organization will be lost. He will shortly send the member countries an invoice on the membership fee.

Following the report of the Treasurer, Frode Larson and Paola Perin propose that discharge be granted to the Board. The proposal is accepted unanimously.

Election of a new Secretary

A new Secretary is to be elected after the death of Carlos Herraiz. Prof. Dr. Gerhard Goebel and Leon Delobbe stand for election, which is conducted by secret written ballot. Seven national representatives with a right to vote are present. Prof. Dr. Goebel is elected with 7 to 1 votes. He accepts the election and will thus act as new Secretary for the current term of office.

Report of the Web Administrator

Conrad Schätz reports that in 2010 the number of persons who visited the website increased by 22 600 to 44 692 visitors. As compared to 2009, that is an increase of 100% (visitor counter: 21 300 versus 11 200 in 2009).

He gives a rundown of the work accomplished in 2010 on EUTi's website. Apart from the monthly talks with Dr. Biesinger, service work on the website and various changes to the national sites, the EUTi logo was modernized and newly designed so that it is now available in sufficient quality (amount of data) for print jobs. The previous logo was only suited for web applications. The new logo was put at the disposition of all member organizations.

The EUTi website was expanded to include the national sites of Poland and Lithuania. The UK site and information on the Italian site were modified. The database was adapted. An evaluation of the MiniTF12 for 2010 to be presented at this meeting was carried out for Prof. Dr. Goebel and transmitted for further analysis.

Conrad Schätz points out once again that descriptions of the disease patterns of hyperacusis, sudden deafness and psychological disorders are missing. Furthermore he suggests that the menu item '*topic of the month*' be either updated or deleted. As regards the MiniTF12, several recommendation texts in certain languages are still missing. Dr. Goebel says that he will see to it.

Presentation of the evaluation of MiniTF12 by Prof. Dr. Goebel

Prof. Dr. Goebel presents an evaluation of the MiniTF12 online questionnaires completed on the EUTi website and draws a comparison with the results of the same test on the DTL website, where a considerably larger database is already available.

Parallels already show up clearly. The MiniTF12 on the EUTi website allows, in addition, to compare results taking into account the different countries with their respective prevailing structures.

Tinnitus Congress in Brazil in March 2011

Dr. Biesinger once again draws attention to the world congress on tinnitus in Brazil and urges to take part in it. Participation can take the form of public viewing. For a one-off amount of 200 Dollar it is possible to watch the congress live and to review all presentations again up to three months following the congress. Registration can be made on the EUTi homepage.

Discussion on EUTi's future

It goes without saying that EUTi will not be able to exist without fund raising. Potential sponsors are, besides TRI, hearing aid companies, publishing houses (Thieme, Springer), manufacturers of MP3 players (Sony, Apple). Courts could be addressed for the allotment of fines. Other possible sponsors: noise generating

industry, banks (work creates stress = tinnitus), universities to initiate art work with tinnitus as topic.

It is clear that sponsors must have a good idea of how funds are going to be spent. The possibility of internet based counselling is discussed in great lengths. Martin Carroll points out that in principle counselling can only be done individually. The proposal is thus viewed critically. The internet can serve as a platform to maintain information provided. Finally, the possibility of setting up working groups to promote EUTi is mentioned. However, there are no concrete proposals as of yet.

Dr. Biesinger closes the official part of the meeting at 16.00 hours. It is decided to hold the next meeting of the members with guests of EUTi on 18 January 2012.