

MINUTES OF THE RETINA EUROPE MEETING IN TORONTO THE 16TH JULY 2000

Rainald Von Gisycki chaired the meeting.

Were present:

Stratis Chapzicharalabous - Greece

Jean Jacques Frayssinet and Karine Burkhardt - France

J.J.L. Martens, Yvonne Van Der Wiel-Rompa - Netherlands

Dave Waldron - Ireland

Stephen F. Jones - UK

Pekka Veli and Seppo - Finland

Mazgozata Pacholek and Elizbieta Tomczyk - Poland

Helma Gussek - Germany

Ole Christian Lagesen - Norway

Philipp Schäppi - Switzerland

Svante Anderson - Sweden

Latasunkert Alapitvany , Dr Alex Franklin , Anthony Haas - New Zealand
as observer

1- The minutes of the last meeting were accepted.

2- Existence of Retina Europe

Rainald proposed to discuss about the will of everybody of building up Retina Europe (what, how, when...) considering what happened during the General Assembly of Retina International (14th July 2000). He admitted that the debate had been discouraging and gave the impression that Retina Europe was no more important. There has been a kind of misunderstanding, a lack of communication. It was decided to let all the delegates express their feeling about this issue.

Alex Franklin said it could be a great idea of distributing to all the ophthalmologists an Amsler Scale. But Rainald intervened to get back to the previous topic: Retina Europe.

J.J.L. Martens gave his feeling: first it is very important that Retina Europe does not compete with Retina International. For example, the money we could get through Retina Europe, would it stay in Europe or could it be distributed around the world? Second, It is important to determine whether we need a legal existence to gain budget from the

European Community or not and whether non-EU scientists can apply for funds or not.

Philipp Schlaeppli said that Retina Switzerland can get EU funds, but he insisted on the point that this money should be used for research and not for administrative work.

J.J.L. Martens added that there is a risk with making Retina Europe that other regions do the same and that Retina International splits.

Dave Waldron explained that we still want to finance research, but we can co-ordinate some international programmes and not only European ones. We can put colleges together without having to create a legal association.

Ole Christian Lagesen: coming back to the Retina International General Assembly, Retina International was not worried about competition but rejected the idea of "thinking regionally". They prefer organising actions on a global level. He asked whether the registration of Retina Europe serve its objective. We can simply build a network. The fact that we could get regional funds is positive but we'd better promote research on a global level. We should only build networks to apply for EC-funds. Retina Europe should be a network of RP organisations in Europe. Non-EU societies can also get EU-funds. The trouble with legal Retina Europe could be that the funds we can get could be absorbed by the administration of the organisation rather than research. This is the main reason of his refusal.

Svante Anderson said it is important to help searchers to get money but he has no idea about the way to do it because he has no experience on the matter.

Rainald Von Gisycki explained Svante Anderson how it works with the EC, the fact that NGOs are the main partner of the EU programmes. He also explained that national societies dealing with other diseases grouped them at the European and the global level. Moreover the EDF may expel Retina Europe because it has no legal existence.

Helma Gussek is ready to get more money for research, but relies on Rainald Von Gisycki for he knows the rules and the methods. Moreover, German searchers have succeeded in get grants from the EC with the RETDEGNET programme.

Stephen Jones gave his point of view before leaving. He feels concerned about the risk that time and grants would be allocated to the running of Retina Europe if it is a legal organisation. Moreover everyone has limited time to devote to Retina Europe. The Retina International General Assembly was concerned and was against it if it is a distraction. It may be too early for talking about a constitution. If the opportunity arises we should try to let the access to the non-EU organisations. It could be an informal network with a leading organisation. Moreover, scientists can apply for funds for other activities. Finally, to deal with the EC is a nightmare : you receive the funds one year after having spent the money. You therefore need a great cash-flow to survive. Rainald confirmed that point.

Stephen: We'd better try like that, then once we have some success, we can foresee a legalisation. Rainald agreed with Stephen. He added that we already had some success (e.g. web site, night vision device). One should build a consortium and it should be lead by a professional organisation, like Empirica.

Mazgozata Pacholek feels it is very hard to manage all interests of all associations, separate countries appreciate the existence of Retina International. It is important to cooperate among close countries, especially EU countries. She confirmed what Stephen said about the nightmare of dealing with the EC. We'd better build a kind of forum with objectives, not only getting funds from the EU. However a legal organisation might bring more administrative work. Let stay a subgroup of Retina International!

Stratis Chapzicharalabous: We should co-operate. It is a good idea of providing scientific programmes. It is quite hard to get EU funds. We'd better have first a few successes.

Pekka Veli: Our main objective is to get money for research. Moreover, we need activities for the further generation, the Youth. He had no idea on the legalisation of Retina Europe.

Philipp Schächli: The Swiss society should go one with funding research. It is concerned about an eventually split of Retina International and the fact that we are losing the feeling of unity. Retina Europe can exist, but it should function without reducing the budget of Retina International and Retina International should use Retina Europe as a tool. Retina International has the total priority over Retina Europe, there no place for

competition. Rainald: Retina Europe was not meant to compete Retina International, but it was meant to remain a subgroup of Retina International. It should be no exclusion. The only thing is: how to get the funds from the EU and how to allocate them?

Jean Jacques FRAYSSINET said he thinks we should all try to work together by a simple action, the Youth Programme. Let's organise them an annual meeting, changing of country every year.

Rainald resumed the situation as follow:

- Retina Europe should remain an informal subgroup of Retina International;
- The budget of Retina International should be untouchable;
- We should create an Email for Retina Europe;
- We reached a basic agreement on what we should do: go on supporting research and the Youth Programme.

J.J.L. Martens insisted on the fact that we should first find out the requirement and demands of the EC.

Anthony Haas explained that the breakfast following the General Assemble, the Management Committee members met about the Asian-Pacific region and the possibility of founding a group. With Gordon COUSIN, they reached an agreement on forwarding membership and preparing the 2002 Conference in Japan. They voted a budget for travels. Rainald explained that we have different needs in Europe.

Rainald suggested to build up a taskforce that should work on the theory of constituting a legal group in Europe and how to hold the EC. It should define the organisation of Retina Europe; its membership fees and the EC requirements to apply for funds. Members this committee: France, Germany and Ireland. We should ask Stephen whether he or anybody of his society joins us in that committee.

Svante Anderson suggested we could ask some scientists for their opinion.

Programme Action Youth

Greece hosts the first conference for the youth. Each organisation should send two delegates in October. J.J.L. Martens suggested to

organise a parallel session with the next meeting of Retina Europe in Warsaw, in August 2001, from Friday evening to Sunday evening. Confer to Stratis.

Programme Action Research

Rainald explained he gets no feedback about the projects he sends us. Should he go on or should he stop? We need a systematically structured activity. Therefore, we create a committee whose members are Dave Waldron, Helma Gussek, Svante Anderson. Again we should ask Stephen Jones whether someone at the UK RP society could join the committee.

Bank account

Retina Europe has an account in the Netherlands, which used to be managed by Charles STEIGER.

J.J.L.MARTENS said that Christina Fasser offered to have an other Retina International account for Retina Europe. We can close the present account and Philipp SCHLAEPPI will open another one in Switzerland.

Fees for Retina Europe: 100 \$

This fees are used to pay fees to European organisations like EDF. However paying fees should be voluntary. Poland could pay, but there are already 300 \$, so they won't pay this prime. RP Switzerland can also pay. RP Greece is OK but needs an invoice (Philipp needs to discuss with Christina about the laws to see the possibilities of making Retina Europe letters)., Finland, the Netherlands, Germany, France, Ireland will also pay but need an invoice too.

The treasurer will be Christina Fasser if she confirms.

Stratis asked whether the EU funds this kind of meetings. Rainald said he had to apply for it. Stratis suggested to try and get reduced prices or have these meetings on Internet.

Dave suggested to build up the network for the youth exchanges and to work on it with Karine and Stratis.

Stratis informed us there was a film to come out end of November on a young guy visually impaired who has difficulties at school The director of the film could intervene at the Youth meeting. Moreover, There is a cartoon to come out in Greece on the retinal degenerations, in which specialists are interviewed.

The next Retina Europe meeting will take place in Warsaw the 1st to 3rd August, 2001.

Sum up of the decisions taken during the meeting:

About Retina Europe

A workshop should find information about how the EC allocates funds to associations. Before we decide about legalising its existence, Retina Europe should have some successes.

Members this committee: France, Germany and Ireland

About research

Creation of a committee whose members are Dave Waldron, Helma Gussek, Svante Anderson, to common projects.

About the Youth program:

The first conference for the Youth will take place in Athens, from 2nd to 5th November, 2000.

Creation of a network for exchanges - contacts: Stratis and Karine

About the financial aspect:

The account in the Netherlands will be closed and another one will be opened in Zurich and managed by Philip Schlaeppi. The fees are 100 USD and based on a voluntary payment.

Next meeting : 1st - 3rd August, 2001 in Warsaw



I AM SORRY !!!



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