

General Assembly

IOYR - International Organisation of Youth with Rheumatism
Thursday 26th July 2001 at Haraldvangen, Hurdal, Norway



Accredited representatives of the member organisations who were present:

1. Romana Lukášová (Czech Republic)
2. Dorte Rønsler (Denmark)
3. Tiina Kriikkula (Finland)
4. Muriel Scheuer (France)
5. Kirsten Ruß (Germany)
6. Gabor Kurtosi (Hungary)
7. Cesare Patara (Italy)
8. Signe Bicule (Latvia)
9. Vilma Bandzeviciute (Lithuania)
10. Lucinda Blauw (Netherlands)
11. Georg Hodnefjell (Norway)
12. Karolina Piotrowska (Poland)
13. Ingrid Kósová (Slovakia)
14. Tomaz Smole (Slovenia)
15. Julio Aguado Cañamares (Spain)
16. Mattias Svensson (Sweden)
17. Laura Margulies (Switzerland)
18. Catherine Gibb (United Kingdom)

Other representatives from some of these countries and representatives from non-member-countries, Austria, Belgium, Estonia and Iceland.

Guest: Per Aage Bjørke (Norway)

Agenda:

1. Opening + welcome (+ voting about minute taker and representative of Spain)
2. Welcome by Moderator
3. History of IOYR
4. Group discussions
5. Plenary Session
6. Election of Chair and Board Members
7. Closure

Lucinda Blauw, Chair of IOYR, opened the meeting

The new members Italy, Latvia, Slovakia and Slovenia were welcomed to join IOYR.

Then agreement was asked of Marianne Scobie from United Kingdom to take the minutes of the meeting, everybody agreed.

Lucinda Blauw gave apologies from Spain; the representative was still on the way to the meeting. The representative is a staff member and does not have arthritis, so a vote was taken to allow him to vote for Spain in the IOYR election. Everybody agreed.

Per Aage Bjørke was welcomed to the meeting.

Address by Per Aage Bjørke, president of 'Norwegian Rheumatism Association' and 'Arthritis and Rheumatism International'. ARI has 21 member countries and the organisation is similar to IOYR.

Per Aage gave an overview of the General Assembly, the importance of discussion of new ideas to set the scene for IOYR and member organisations and give ideas for the future.

Lucinda Blauw gave a presentation about the history of the IYC's and IOYR

First IYC was organised by the Dutch Youth Committee in 1989, 40 participants from 14 countries. The theme was "Rheumatism in International Youth Perspective".

Second IYC took place in the UK in 1992, 45 participants from 16 countries. The theme was "Removing Barriers towards Independence".

Third IYC in Denmark, the theme was "From Separation to Co-operation".

Fourth IYC in Germany, 47 participants from 16 countries. The theme was "Quality and Equality".

After second IYC a working group was started to work on setting up an international youth organisation, so in between youth congresses people could stay in contact with each other.

In period 1998-2001 the board of IOYR has been busy with:

6 Board meetings

8 Manifesto meetings (Michael Bernardy will discuss this on Friday)

3 EULAR Congresses

2 World Wide Conferences

1 Open Day in Copenhagen

4 Newsletters + 1 Special Edition for IYC

4 New member countries

During the last EULAR Congress in Prague 5 IOYR Board members were able to go. They gave presentations about living with rheumatism and about IOYR.

During the Open Day in Copenhagen 8 countries were present with 13 persons, 2 of them from mother organisations. During the day projects were discussed and ideas were shared.

The General Assembly has to discuss the possibility of another Open Day.

IOYR has got a homepage. Thanks from everybody to Dorte Rønslér (Denmark), Jette N. Pedersen (Denmark) and Cesare Patara (Italy) for setting this up.

Per Aage introduced group discussions. 6 groups with group leader and secretary to take notes and present the results in the plenary session. He stressed the importance to have opportunities to learn from each other and that these discussions will point the way forward to the board.

Groups had 1 hour to discuss the topics.

After the break Per Aage was voted as neutral person to oversee the election.

Plenary session – feedback

Julio Aguado Cañameres - representative from Spain arrived during the feedback session.

Group 3:

Homepage:

Already good / would like chatroom more established

Like planned chatroom i.e. specific date / time board member available to answer questions / live debate

Get all info on member organisations

Newsletter:

Few people receive it as it goes to main organisation
Send to international contactperson to forward
2-4 times a year is good
People can sign up to the mailing list

Sponsorship:

Agreement over ethics of advertising from companies who give us money

Group 4:

New Members:

Write PR newsletters / send to rheumatism organisations / places where people with rheumatism meet
Include debates in newsletters

Membership fee:

Change to 200 Euros / suggest no fee for associated members / suggest supporter members who pay

Aims (in constitution):

- 1.1 take out phrase Eastern / Western Europe
- 2 add "initiatives" after "other organisations with similar interests"
- 11 inauguration statement to be taken out

Sponsorship:

Money to be applied for specific projects
Never have just one sponsor

Newsletter:

Remind organisations to send it to the members
Annual report to IOYR board from member organisations to be published

Group 2:

Aims:

OK, but add 2.4 lobby for change to practical matters
Involve 'healthy' people (non-disabled, family, friends) to help us
Add program to educate health professionals
Lobby work

Constitution:

Age (currently 18-35) what is the flexibility and if so it should be written down; rules regarding this
Also world international in point 1

Membership:

Assign person on board to source

Homepage:

Links between IOYR and member organisations
Use it to raise money
Include medical information

There was a discussion on the pros + cons of including medical information on IOYR website.

Partnership:

Board projectgroup to work more intensively to support countries

Group 6:

Constitution:

Suggestion to add process of General Assembly including how to vote / neutral person to oversee

Annual report to be published – also useful as PR

½ day workshop on constitution at next IYC

Partnership:

Debate on IOYR to coordinate or left to individual countries to organise

Membership fee:

Agree on change to Euros

Encourage support to poorer countries and richer countries to give more

Value for money to be promoted

Max fee with %age below depending on how much money / many members

New members:

Be proactive – web / publications / conferences

Projects:

Needs analysis of all nations to find out what needs to be done

Establish / facilitate partnerships

Open Days to continue

Lobbying

Disabled Peoples International – priority to join

Group 1:

Open Day:

Good idea to introduce ourselves + share info

Would like Open Day every 18 months with one from mother organisation + 2 from youth

Sponsorship:

Someone from IOYR to fundraise / working group

Find international money

Newsletter:

OK. Better to ask countries to represent themselves

New Members:

Outside Europe: make contact

PR to other countries

Group 5:

Open Day:

Have 1 in between IYC
Offering to members to showcase ideas
Adds value to IYC
Contact with board continuity

Sponsorship:

Some nations sponsor others to attend events
Letters from board to mother organisations to ask for support; giving quality feedback
Research into funding
Find sources of funding to host Open Day
Dilemma of taking money from drug company
Develop simple ethical policy for IOYR

Newsletter:

More good quality info into newsletter
General info including treatments / access
Report from Board meetings in newsletter

Constitution:

Age limit – whether to change it or not

All groups were thanked for their participation and suggestions to the board.

Suggestions to Board to appoint a group to look at constitution to suggest changes.
Agreed that board can decide on the membership of that group and the process involved in making changes. Any suggestions for changes will then be sent to members for consultation.

Election

Treasurers report:

Accounts have been sent out in advance.
Accounts should normally be audited – however they have not been audited. Can the General Assembly accept non-audited accounts?
The accounts were accepted as true account for the last 3 years.

Election of Chair

Dorte Rønsler standing for chair.
No other candidate stood for chair – Dorte Rønsler was duly elected.

Presenting the candidates for new board

Candidates standing for election gave a short presentation about themselves.

- Georg Hodnefjell → BURG – Norway
- Kirsten Ruß → Rheuma-Liga – Germany
- Vilma Bandzeviciute → Kaunas klubas “ARTRITAS” – Lithuania
- Vanessa Spitzer Rubio → LIRE / AJER – Spain (represented by Julio Aguado Cañamares)

- Lucinda Blauw → Rheumatism Patients League – The Netherlands
- Laura Margulies → Rheumaliga - Switzerland
- Karolina Piotrowska → SMCNPZS – Poland
- Catherine Gibb → Young Arthritis Care – UK

Per Aage introduced the voting slips. The voting slips would be counted by Peter de Oude and Sietske Tadema.

Votes: One per country, up to six names → name of country + name of person.

Fee

As the vote was counted there was a discussion regarding the fee to join IOYR. It was agreed to take some decision to increase the fee and change the payment to Euro. £100 will be 160 Euro. There were questions as to why the fee must be raised.

For: Has been same fee for 6 years / will be able to do more / will be able to use the money for travelling costs to meetings and conferences.

Against: More countries might not be able to pay / members will expect more.

- Agreed (minus one) that the board has authority to suggest the fee for the membership and have postal vote to ratify
- Agreed unanimously that the fee is paid in Euro's
- Agreed unanimously that the board suggests a fee for associate members and has a postal vote to ratify

Results of the Election to the Board

It was agreed (minus one) that only new board members will be shown, not the number of votes for each candidate.

There was a tied vote between Poland and Lithuania, so a second vote was taken to decide who remains on the board.

The votes were as follows:

- Norway
- Switzerland
- Germany
- United Kingdom
- The Netherlands
- Lithuania

Lucinda Blauw congratulated the new members to the board and thanked Per Aage for facilitating.

Everyone was reminded to sign the card for Montse from Spain.

Per Aage was presented with an IYC t-shirt and cup.

Dorte Rønsler said thanks for the election as chair. She looks forward to the work and reminded everyone that they shall also be active over the next 3 years. She also thanked the old board and welcomed the new board members.

Dorte also told that the board will write to member organisations regarding the constitution.

Per Aage thanked everyone and closed the meeting at 6.40 pm.

Minutes

Marianne Scobie