

**BURG**

**BARNE- OG UNGDOMS-  
REVMATIKERGRUPPE**



*IYC 2001*  
**Norway, 21 - 28 July**

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**International Youth Congress**  
for young people with  
rheumatism

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**THE POWER IN YOU**

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*How to make international co-operation  
a platform for growth*

**Nations present:**

Austria - Belgium - Czech Republic - Denmark - Estonia - Finland - France - Germany - Hungary -  
Iceland - Italy - Latvia - Lithuania - The Netherlands - Norway - Poland - Slovakia - Slovenia - Spain -  
Sweden - Switzerland - United Kingdom

**Report**

# IYC 2001 - Norway

**IYC 2001, the International Youth Congress for young people with rheumatism, was arranged and hosted by BURG (The Norwegian Rheumatism Children and Youth organisation). The congress is held every third year initiated by IOYR (International Organisation of Youth with Rheumatism).**

## PREPARATIONS

### *The decision*

The decision to apply to host the IYC 2001 was made by the BURG board in autumn 1997. The decision was unanimous. An enquiry was directed to the IOYR board, and they happily accepted.

### *Projecting*

Georg Hodnefjell, member of the BURG and the IOYR board, and Rolf Husebø, former chair of BURG and BURG's international representative 1989-1995, had made all inquiries and developed the project description which made basis for BURG's decision to apply. They now continued their work as the first members of the "IYC Project Group". Later Georg was appointed to be Project Manager.

### *Joining the IYC 1998, in Berlin*

The first real announcement of the IYC 2001 in Norway was made at the IYC 1998 in Berlin, Germany. Georg, Rolf, Annette Haukås and Lars Espen Rath Vestad participated with one common goal in mind; marketing the IYC in Norway.

Annette and Lars Espen were at that point both leaders of regional BURG branches, and were both handpicked to join the Project Group. (In 1999 Annette and Lars Espen became members of the BURG national board).

The last couple of days of the congress in Berlin, the Norwegian delegation wore T-shirts saying in front; "Welcome to Norway", and on the back; "IYC 2001 in Norway". Also, at the end of the program, the Norwegian delegation was given room to make a "next IYC presentation". For this event the Norwegian delegation had prepared "a Norwegian taster": The Norwegian participant wearing national suits handed out finger-food of Norwegian specialities and Norwegian liqueur. All accompanied by Norwegian music and pictures. In this atmosphere we presented "our congress", handed out a preliminary announcement, and invited everybody to "come to Norway".

The Project Group learned a lot from the Berlin congress. Already in the car leaving Berlin, notes were made to catch the ideas we had picked up.

At this early stage of the preparation, the Project Group's main focus was on four subjects:

1. Announcing
2. Raising funds
3. Continue the process of drawing the picture of "our congress to be"
4. Finding a location for the congress

### *Announcing*

Announcements were made to, and through, all members and contacts of the IOYR, including all former IYC participants. ARI (Arthritis Rheumatism International), EULAR (European League Against Rheumatism) and similar organisations were used as channels for contact, as well as the rheumatologist's international network. Announcement folders were also distributed at several international exhibitions and congresses, and information was spread on the Internet.

### *Raising funds*

We aimed to get 70 participants to the congress, coming from all over the world. We aimed to make it possible for young people in the target group to join the congress, even if their own economy or their organisation's (if any) did not allow it. And, we aimed to make it the best IYC ever.

These ambitious goals required a lot of money. Applications were made to governmental and non-governmental sources inside and outside Norway. A lot of effort during the planning period was directed towards possible sponsors; writing letters, filling out application forms, follow-up of possible and actual sponsors, budgeting, reporting and so on.

More than 120 sponsors were contacted through the process. A total income of ca. 800 000 Norwegian Kroner was the result.

These excellent companies and organisations supported us with money or with practical help:

Acta • Pharmacia • Ung i Europa • Helse og Rehabilitering • Nordisk Reuma Råd • SUAK/Internasjonale prosjektmidler • LNU/Demokratimidler • Sigval Bergesen D.Y. og Hustru Nanki's Almennyttige Stiftelse • Buggeland Vaskeri • Sundal Collier & Co • Handelsbanken • Accenture • Human Link • Norsk Revmatikerforbund • Hans Majestet Kongens Garde

### *Drawing the picture of "our congress to be"*

The Project Group's work was carried out by individual work, telephone meetings and actual meetings. Most meetings were located in Rolf's apartment in Bergen. Through weekends of teamwork "our congress" found its form.

We wanted:

\* to make the congress an important milestone in every participant's life. We wanted everybody in particular to gain some new insight and a lot of power for themselves. And we wanted their fellow young people with rheumatism, in their own countries, to get some value too, through our participants' new-won insight and power.

\* people to go home, inspired and qualified to build strong national organisations.

\* to encourage co-operation between countries, and we wanted to give the participants some tools, which they could use to make this happen.

\* to strengthen the international co-operation, within the framework of the IOYR.

Based on these conditions we drew up the picture of "our congress to be". The picture looked like this:

We quote:

*We'll give our congress the title:*

*How to make international co-operation a platform for growth*

**THE POWER IN YOU**

*"The power in you" describes the power that exists in every human being, the possibilities for self-development, the power to break barriers and to manage their own life. How can we do something active to change or improve our own situation, and how can we use our "strength" to influence the society we live in and are a part of? It is all about being active, taking responsibility for your own life, and seeing that the possibilities are endless also for us having a rheumatic related disability.*

*The young people who will meet in Norway in 2001 have in common that they are involved in organisations or want to be involved in the work for young people with rheumatic related disabilities in their home country. Experience shows that there is an obvious connection between what an organisation gets done for their group, and the power, knowledge and fighting spirit of those who run the organisation. The development in a country will have to start with the people living there, and we find therefore that personal growth is an especially important brick in the work for develop and strengthening the national rheumatism organisations. Through the term "The power in you", we feel that we have found a slogan that expresses exactly the connection between personal power and the power of the organisations.*

*All parts of the program, professional and social, will be built around this idea.*

### ***Finding a location for the congress***

We were determined to find the "right place" to arrange our congress. Members from the Project Group travelled around Norway to find it, until Lars Espen visited Haraldvangen. Than he knew at once that this was the place. And he was right. Haraldvangen offered just the facilities and the atmosphere that we were looking for. Haraldvangen was for sure the place that would give the right frame for our congress.

### *Hard work*

During 1999 we found it necessary to strengthen the Project Group even more. From BURG we recruited Linda Wøllestad, Janette Henning and Trine Normann Olsen. Trine had, as BURG's paid secretary, supported the Project Group from the beginning but now she joined the group as a full member. We also included Dorte Rønsler, IOYR board member representing the Danish Youth Organisation FNUG.

As we moved closer to the congress the workload escalated, and put a heavy burden on all the Project Group members. The Project Manager Georg, especially, was under much pressure, co-ordinating, supervising and in many cases executing the work.

At this stage all tasks connected with the congress were in process. Among the tasks we can mention:

Raising money • Program work • Announcing to get new participants • Talking and corresponding with people who had announced their interest • Talking and corresponding with confirmed participants • Project Group, team-building and support • Finding and hiring lecturers • Instructing, and interacting with lecturers • Recruiting helpers and get hold of help-remedies • Reporting to and interact with IOYR • Interact with Haraldvangen • Follow up on sponsors, talking and corresponding • Reporting to and interact with BURG and NRF • Support the "congress idea" inside the organisation by writing articles in the member magazine, giving lectures and so on • Support the congress idea through information and marketing in national and international forums, on conferences and similar • Identify and execute all big and small tasks that have to be fulfilled to make the congress • Decision making • And more...

### *Co-operating with the IOYR board*

All through the planning process the Project Group was communicating with the IOYR board, through board members Dorte and Georg. In March 2001 the IOYR board was invited to a meeting at Haraldvangen, to go through the congress program, and to look at the location and the facilities.

## **PARTICIPANTS**

75 persons, aged 18 to 35, from 22 countries signed on to the congress. In the budget that made the basis for all our fund-raising activity, money for covering costs for selected participants a big item. We did not want people to miss the congress because their organisation (if any) couldn't raise the necessary money. Finally costs for 20 foreign participants were covered by the IYC project. And, every country that wanted to join the congress was represented.

## THE CONGRESS

### *Program support*

The responsibility of preparing and giving a content to the different days and the different themes in the program was shared within the Project Group. To help us, to actually lead us all through the program and to support the learning and sharing process, we had brought Kate Nash over from London to be our facilitator. Kate is former Deputy Chief Executive of Arthritis Care, and was head person responsible for the IYC in Coventry, England in 1992.

From the Project Group, Georg, Rolf and Dorte were responsible for the program. Their job was to monitor the "quality of the process", as the program was moving forward, and together with Kate propose, and when needed, perform changes. The goal was to do what was best for the process at any time according to the congress idea. Not to statically stick by the original plans and schedules. And adjustments were made, all the way.

### *"Taking care of business"*

The entire Project Group shared responsibility to take care of everybody's wellbeing at all time. Regarding most practical matters, the technical team with Lars Espen, Annette and Linda, the secretariat with Trine and Janette, and the helpers Torbjørn Midtgård and Eirik Oen Lie handled the most. The Project Group also worked closely with the staff of Haraldvangen to make sure everyone's needs were met.

One very popular activity was the Internet Café. Every day (and some of the night) the Internet Café was up going, and participants could update their own homepage, check e-mail or write day to day information to their local Newsletter. BURG-members Helge Elvik and Andreas Gunleikskås, who was running the café beside of taking care of all computer-related jobs and problems, did a great job that was highly appreciated.

All members of the Project Group carried out a lot of work during the week. Among the tasks we can mention:

Transport • Room-Tidying • Do beds • Practical assistance • Personal assistance • Adjusting the agenda • Evaluation • Shopping • Rearranging rooms • Change scenery • Replacing banners and more • Being hosts • Presence • Producing written material • Writing articles for different national and international homepages and newsletters • Taking care of visiting speakers • Running the secretariat • Responsibility • Leadership • Taking pictures • Preparing for the Trombinoscope • Running the Internet Café • Running the karaoke machine • Serving drinks • Being available and giving time to everybody • And more...

## ACTION DAY BY DAY

### *Saturday 21 July*                      *Arrival day*

A large group of BURG-members were present at Oslo International Airport Gardermoen, meeting and assisting the participants as they arrived during Saturday morning. We had arranged for our "staff" to get extended access at the airport, so they could enter the customs area and meet people as soon as they left their planes. Eventually groups of participants were brought to Haraldvangen by bus.

At Haraldvangen a new group of BURG-members gave all participants a warm welcome and helped them get settled.

At 7pm everybody was present at Haraldvangen, and BURG Chair Ragni Bilberg officially opened the congress. The opening ceremony was a short but eventful happening, which managed to set a good atmosphere for the week. Everybody present got a red rose from the Project Group as they arrived. Ragni Bilberg, Project Manager Georg Hodnefjell and IOYR Chair Lucinda Blauw, The Netherlands made speeches.

Kate Nash, our facilitator for the whole week, presented herself and led us through an "ice-breaker". Everybody had to exchange roses with someone, and perform a little conversation. Also, we had to pull a name from a hat, and be "a secret friend" for the person whose name we had drawn for the whole week. The opening session was completed with Lars Espen, playing some beautiful music on his Trombone. (A thing he actually did every morning during the week to wake up people).

After a long day of travelling, lots of the participants were tired and took an early evening. Others started "the social program" at once.

The Project Group, who had to use every spare moment to think about the program and everybody's wellbeing, could conclude that the first day had been a success, and that the congress was "up and running".

### *Sunday 22 July*                      *Motivation through presentation*

*Purpose of the day:*

- *To make everybody present understand the idea of the congress, and set the atmosphere and "the level of the exchange".*
- *Getting to know each other by letting everybody present themselves, their countries and their organisations.*

To explain our slogan for the week "The power in you" we had hired Kåre Dreyer. Through lectures and exercises Kåre showed us how we can make our hidden power come to the surface, and how to use it more efficiently. The power is often blocked by our subconscious.

He talked about how we have a tendency to let others judge us - or more exactly "judge ourselves on the basis of how we think others judge us". Kåre pointed out for us that "we ourselves" are the only ones that can create our life, and that we cannot reach very far if we choose to blame, or place the responsibility, on others.

After a splendid lecture we had lunch at "Eidsvoll tunet", a museum showing Norwegian traditions. The museum is located at Eidsvoll, where Norway's first constitution was signed in 1814. At "Eidsvoll tunet" authentic buildings and tools from a 1600 century farm are kept, and on show for the public. Everybody appreciated the visit, but some did complain about our food-surprise, the traditional Norwegian "Rømmegrøt".

After lunch we made posters. Every country created their own unique poster, showing their country and their organisation. Than the posters where installed in the plenary room, making a wall exhibition.

General Secretary Lisa Yttersrud visited us as we worked, bringing her greetings from NRF The Norwegian Rheumatism Association.

In the evening everybody was invited to a "party in the lavvo". The official entertainment of the evening was an "old" lady telling traditional Norwegian fairytales. During the night we also got to enjoy several talented participants sharing their talent with us - playing guitar, singing and more. In the lavvo, by the lake, drinking "something" from handmade wooden tree-cups given as a present from the Project Group, we enjoyed a long and very good party.

### ***Monday 23 July                      Breaking barriers***

*Purpose of the day:*

- *To explore our internal and external barriers and share experiences about how they may be overcome.*
- *By using personal stories challenge ourselves to find the power in us.*
- *By participating in physical activities, challenge ourselves to find the power in us.*

In the morning session we focused on barriers by talking about it.

To introduce the subject "Breaking barriers" Rolf from Norway made a presentation. Rolf used his own life and his own story to exemplify what our barriers can be, and how they can be approached and sometimes overcome. Rolf's main message was that we should not limit our life because of our rheumatism. Problems that force us to adjust our behaviour, reduce our possibilities, or change the way we look upon ourselves, need sometimes to be "challenged" to see if they are valid. Is it actually the rheumatism that determines the limitations? Or could it be that the limitations are caused by barriers we have constructed ourselves in our own minds?

Rolf underlined that you do not necessarily have to change even if you find there are no actual barrier that stops you. But, you should know then that you do what you do because you chose to, and not because your rheumatism makes you.

After Rolf's speech the participants were challenged to test out their own barriers. Through several "4 Corners" exercises (diversity and dialogue) directed by Kate, each participant personally had to take a stand in different matters that a young person with rheumatism is likely to be confronted with in life. Subjects like "having children" and "are we willing to expose our rheumatism?" were touched.

The afternoon we spent outside, challenging our barriers doing physical activities.

Alternating between activities such as sailing, water-skiing, canoeing, fishing, horse riding and making speeches, the challenges were many, and probably everybody did at least something for the first time. Undoubtedly it was quite a stunt most of us taking part in these "extreme-sports" but everybody did join in, and everybody had a fantastic time.

To fulfil the idea of the day, we spent the evening challenging our barriers singing karaoke.

## **Tuesday 24 July**                      ***Owning your own health***

*Purpose of the day:*

- *To explore how we can own our life- choices and decisions.*
- *To examine the things that help (make easier) or hinder (make more difficult) how we own our health as a part of our life.*
- *To explore how we move out of our comfort zones, and challenge low expectations of ourselves.*
- *To examine how we can achieve balance in our life and keep our dreams e.g. having a child or being the president of the country.*

Kate wanted us to see why is it important to develop ownership of our health and our life, and what happens if we choose not to take control. Kate challenged each one of us to think through how we are in control of our own life, and how our disease influences our life expression. Through short kick-off lectures, followed by group-discussions, we used each other's experiences and thoughts as "mirrors" to get aware of our own stand, and our own conscious and unconscious strategies to "gain control".

After lunch Hege Koksvik from the "Centre for mothers with rheumatic disease" gave a lecture. The centre is located in the Norwegian town Trondheim, and gathers information and performs research on medical, social and practical issues relevant to people with rheumatism. Challenges and possibilities concerning having and raising children were identified and discussed.

Then, after the plenary session, those with a special interest in the subject were invited to learn more by joining one of two parallel programs.

One important message from Hege was that having a child is a personal choice. When making that choice, having a rheumatic disease is only one important but not definitive factor to consider. The "Centre for mothers with rheumatic disease" offers information

and advice to people also outside Norway, and all participants and their national contacts were invited to get in touch.

At the same time as Hege guided her group through questions regarding having a child, Kate led a parallel session about “balancing priorities in life”.

In the evening an international party was arranged. People had brought specialities from their own countries, food, clothes, a performance and more, and presented it at the party that was dedicated to “cultural sharing”. People put a lot of effort and creativity into their “show”, and made an exotic and eventful evening for all of us. Really something to remember.

### ***Wednesday 25 July            Excursion to Oslo***

*Purpose of the day:*

*To explore the capital of Norway, Norwegian culture and street life.*

Wednesday we spent the whole day “doing Oslo”. Just as at the arrival day His majesty the King’s guard supported us with “Royal” busses and drivers.

The Oslo excursion started at the Akershus harbour where we entered a Viking ship. We spent four hours in the Oslo fjord cruising in beautiful warm and sunny weather, eating seafood while we enjoyed the beautiful view. When getting solid ground under our feet’s again, we spent an hour “on our own” shopping or otherwise. Then the bus took us to the “Vigelandsparken” where we enjoyed a strawberry-champagne picnic.

That evening there where no organised happening, just the “usual” party and karaoke.

### ***Thursday 26 July            In to the future***

*Purpose of the day:*

- *To hear news from science and new treatments for rheumatic related disabilities.*
- *To have the IOYR General Assembly.*
- *To hear about the history of the IOYR and discuss the future.*

Professor Dr. Med. Øystein Førre from Rikshospitalet, Norway started the day by presenting news in medicine. From Dr. Førre’s presentation we learned that there is some kind of a revolution going on in the field of research on rheumatism medicine. Until the last few years, mainly symptoms have been treated and suppressed. Medicine directed to moderate the actual disease, have had a quite “wide” approach attacking the immune system as a whole. The new regime of medicines, the so-called “TNF alpha suppressers” have a much more accurate approach hitting directly at the problem. The medicines on the market at this point reflects just the first little bit of a new knowledge, are extremely expensive and therefore available just for a few. Most certainly it will be exciting to see what this new knowledge will lead to in the longer term. Some participants already were on these medicines, and certainly a lot of others showed interest to know more, and of course also to get to try them.

Thursday afternoon Per Aage Bjørke, President of the Norwegian Rheumatism Association and ARI (Arthritis Rheumatism International), led us through the IOYR General Assembly. More about this in the General Assembly minutes.

That evening there was a barbecue, and the “usual” party and karaoke.

### *Friday 27 July                      From international knowledge to national activity*

*Purpose of the day:*

- *To hear about “who is doing what” in Europe.*
- *To explore the possibilities for international co-operation and have some thoughts about developing partnerships.*
- *To prepare emotionally for our return home.*
- *To reflect on what we have gained from the congress.*

During Friday we got to meet and listen to several people sharing their knowledge about different projects and programs. Something to inspire activities in other countries, and some specific information about programs representing possibilities for us all. But maybe just as important, we started the process of mentally preparing ourselves to leave the IYC fellowship.

First presentation Friday morning was Dorte Rønslér talking about “Me after IYC”. Experience from previous congresses has shown us that attending an IYC generates a lot of feelings. Experience also shown us that these feeling might be difficult to air when you are home, separated from “those who have the possibility to understand”. Dorte told about her personally experiences from IYC’s in 1996 and 1998 and reminded people that it is also important to keep in mind that even though it seems silent and maybe lonely to be back home its important to remember all the friends, the ideas and the inspiration we gain at the congress. Ending her presentation Dorte told that Friday’s programme was made to give even more ideas and also a forum to talk about future co-operation.

- **Christian Hellevang – EU’s YOUTH Program**

Christian presented the different programs run by EU’s YOUTH Program. We learned that there is actually a lot of money available that might even be easy to get. All we need is to make good projects, involving young people from more than one country, and deliver good applications. And, EU’s YOUTH Program employees will provide us with all the help we need in the process. It should be mentioned that EU's YOUTH Program gave us 120 000 Norwegian Kroner, to the congress.

- **Michael Bernardy – Chair of the Manifesto Steering Group**

Michael Bernardy presented the Manifesto for people with Arthritis/Rheumatism in Europe, and introduced us to its aims and activities. He pointed to The Manifesto, a declaration on behalf of over 100 million people with arthritis/rheumatism throughout Europe, as a possibility to reach out and actually make changes.

- Other participants sharing projects

Local and national projects were presented by participants as examples of what is going on in the different countries. Projects to be presented were picked by the criteria that it was “a little special” and maybe ideas that others could copy and develop in their countries.

The last activity in the program intended to give the participants a possibility to express their feelings and thoughts. One hour we spent in a circle, sitting quietly faced towards each other, and a lot of words and emotions about the congress and thoughts about going back home were shared.

In the evening of course there was a goodbye party. The party got a real kick off, starting in the plenary room where drinks were served followed by a Video Show revealing social climaxes from the week. Then we moved to the dining hall, where a gala dinner was prepared. During the gala dinner many positive words fell on the congress, the Project Group and to everybody, the people present.

After dinner the Big-Band “Odd R. Antonsen Hamar storband” played up, opening the dance.

### *Saturday 28 July*                      *Departure day*

Departure from Haraldvangen started already at half past five in the morning, and continued until noon. The Project Group spent some of the evening tidying up, removing every last trace of the IYC 2001.

## EPILOGUE

\* We fulfilled our main goal. We managed to match the idea of the congress. The congress became what we had planned (and dreamed) for it to be.

\* Feedback at and after the congress was absolutely positive. Day to day evaluation, made in writing by the participants, verifies this opinion.

\* All members of the Project Group felt the congress had been a success beyond our dreams.

In his opening speech for the congress, Georg challenged every participant to take responsibility for making the congress a success. After spending almost four years preparing the congress, he and the Project Group was happy to deliver the congress, as an opportunity for everybody present.

In his speech at the final of the congress, Georg directed his thanks to each and everyone for taking him up on that challenge and making it happen. What had characterised this congress was the fantastic atmosphere of friendliness and willingness to include and to share. In that climate the learning and developing process took place, generating power for everybody.

In fact every hour of the congress was an adventure, professional and social. Describing the evenings in the report for instance, we have used the description "usual party". It should be said that nothing was usual at the IYC 2001. All these special people, together, made fantastic gatherings and parties no matter where or when we met.

Thanks to everyone who participated and contributed to make the IYC 2001 an experience for life!

*Written by Georg Hodnefjell and Rolf Husebø*