

Newsletter Health-SIRG

I ASSID Special Interest Research Group (SIRG) for Health Issues

November 2001

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Report on Health SIRG Gotenborg Roundtable 2001

Monika Bjorkman from Sweden was the conference convenor

The program contained reports on recent and planned research in the areas of: Hearing and Visual Impairment, Epilepsy, Nutrition, Gastroesophageal reflux, *Helicobacter pylori* infection. An underlying goal was to present evidence based recommendations.

Vision impairment is a common problem in people with intellectual disability especially in people with more severe disability (more than 50%) and of older age. The nature of the vision impairment may be at the level of the orbit affecting visual acuity or it may be in the cerebrum itself affecting the interpretation of visual signals. In

the latter case, visual acuity may even be normal. Management involves diagnosis of the nature of the vision impairment, which may be surgically treatable. Both specialised behavioural optometrists and ophthalmologists have a role to play in the diagnoses. In cases where there is no restorative therapy, management relies on techniques such as verbal communication and advice, written information, practical advice on lighting, contrast, glare, colour, magnification, referral to other specialists, vision training. Current research on the impact of the optimising light levels, glare, contrast and colour is on going. Drs Jacques van Splunder, Lizbeth Sjoukes, Lena Jacobsen, Sonia Gronquist, Mette Warburg

Hearing impairment may occur as the result of outer, middle or inner ear pathology. It is important to again diagnose the nature of the hearing impairment, which may affect acuity or sound perception and interpretation.

Dr Anneke Meuwese

Formal guidelines for diagnosis and management of epilepsy in people with intellectual disability were presented. The guidelines were formulated using a Cochrane analysis style approach and are to be published in *Seizure* journal in early 2002. The essential features of the guidelines involve a formal diagnosis of the type of epilepsy, which comes from a history, EEG and imaging of the head. Assessing the epilepsy should be performed in conjunction with assessment of the functional, behavioural and other medical aspects of the person with epilepsy and the care setting.

Drs Mike Kerr, Mark Scheepers

A screening nutritional tool was presented which serves as a checklist for carers to determine if the person with intellectual disability has or is a risk of a nutritional problem. Formal validation of the tool has not yet begun but its use anecdotally has been found to be successful.

Ms Lyn Stewart

Research data was presented showing that the prevalence of gastro-oesophageal reflux is up to 70% in people with cerebral palsy, with severe intellectual disability or using benzodiazepines. Not only can this condition cause severe pain, it leads to complications such as Barrett's oesophagus and oesophageal cancer, which were shown to occur more frequently in people with intellectual disability compared to the general population. The symptoms may be atypical or unrecognised. Thinking of this diagnosis in any person with these risk factors followed by careful history and consideration of confirming it with endoscopy could prevent painful symptoms and reduce morbidity and mortality by treatment with proton pump inhibitors.

Dr Clarisse Bohmer

Helicobacter pylori infection is endemic in those people with a history of institutionalisation. Having more disability, more behaviour problems, living with flatmates with hypersalivation or faecal incontinence were also shown to be independent risk factors for infection in any residential setting. Patients may not have any

overt symptoms. The literature suggests that peptic ulcer disease and gastric cancer, complications of this infection also occur more frequently in this population. Although there is little evidence that eradication of the infection causes change in maladaptive behaviour or functional ability, morbidity and mortality from this infection may be reduced by eradication of *H.pylori*. The meeting did not reach consensus on the matter of screening of high risk sub groups.

Dr Robyn Wallace

[Report of last five year=s progress on health SIRG by outgoing ChairpersonB Dr Heleen Evenhuis.](#)

Chairperson=s Report, September 22, 2001

1. Introduction

This chairperson=s report is for me a special event because of two reasons: first because our SIRG has existed and been active now for five years, and second because this is my last report as your chairperson. Because of my commitments at the Rotterdam Chair of Intellectual Disability Medicine and staffing issues, I am no longer able to fulfill this task in the way it should be done.

After a short overview of our activities during the past five years, I will give you a summary of the SIRG=s activities and contacts during the last year.

2. The SIRG during 1996 - 2000

During the IASSID congress in Helsinki, Finland, in July 1996, Helen Beange and I took the spontaneous initiative to found this group. We felt that congress contributions in the field of medicine were underrepresented, whereas in our opinion, much more medical and related research had to be done. We checked with the IASSID chairman-to-be-chosen, Trevor Parmenter, and with council members of the European Medical Association on Mental Handicap (MAMH), getting positive and supporting reactions. In a preparatory meeting with around 40 colleagues, we founded the Special Interest Research Group on Physical Health. Helen Beange and I were nominated as the deputy chairperson and chairperson, respectively.

Together we formulated the following aim: to promote physical health of people with intellectual disability by formulating priorities for health care, research and training, and by sharing ideas and results. Activities would be annual roundtables as well as the preparation and

coordination of contributions for IASSID and MAMH congresses.

In September 1997, we held our first roundtable in Leiden, the Netherlands, with as central theme the early detection and diagnosis of visual and hearing impairment. Key speakers presented recent advances in diagnosis in non-cooperative persons and hearing aid fitting and training, short free papers were presented by members, and the afternoon sessions were dedicated to work on an international consensus statement. A proposal to found a new SIRG on sensory impairments was considered premature at this stage, but we decided that sensory impairment would remain a central, multidisciplinary topic of our SIRG. One session was dedicated to discussion on a preparatory document on health targets, prepared by our Australian colleagues. During the general meeting, a steering committee was elected, which has functioned until this day.

The second roundtable was held in June 1998 in Manchester, UK, prior to the second international MAMH conference. Here we worked further on the draft health targets document, and we completed the consensus statement on visual and hearing impairment. We further had a session on syndrome-specific comorbidity.

During the general meeting, the following priorities were recognized for future roundtables: *sensory impairment, epilepsy consensus, endocrine disease, pain, cerebral palsy, diagnosis and etiology of intellectual disability, primary care, end-of-life decisions/palliative care, oral health and dental care*. It was stressed that all such work should be underpinned by an evidence base and the potential for a future session on trial methodology was welcomed. In November 1998 the final consensus statement on visual and hearing impairment was published by us and sent to all members and to the IASSID Council.

Our third roundtable with ageing as the central theme was a successful joint event with the SIRG on Aging. It took place in April 1999 at the World Health Organisation (WHO) in Geneva. The goal of this meeting was to address the request received by the IASSID from the WHO to examine the health aspects of ageing of persons with intellectual disabilities and to provide recommendations to the WHO on how to promote longevity and healthy ageing around the world.

Apart from the shared sessions, we had our own sessions on 1. Health targets and primary care,

2. Mobility impairment, falls and fractures, 3. Diagnosis and differential diagnosis of dementia, and 4. Comorbidity and ageing in cerebral palsy.

Prior to this meeting, four background papers on healthy ageing were written to be discussed during the roundtable, respectively focussing on Physical health, Mental health, Women=s health, and Ageing & social policy. These reports have in January 2000, after their completion, been submitted to the WHO. The health targets document was also completed after this meeting.

In June 1999, the SIRG on Physical Health was formally recognized by the IASSID Council.

In the year 2000, no roundtable was organized, because of the 11th IASSID World Congress, which was held in August in Seattle, USA. However, we organized a general meeting and a two-day pre-congress update course on visual impairment, with workshops and practical training sessions on the personal experience of visual impairment, frequent causes and risk groups, behavioural signs and behavioural problems, and assessment. This course was attended by 9 participants and 8 lecturers and trainers. During the congress, our members contributed with a range of papers. Unfortunately, in spite of a preparatory meeting of representatives of the formal SIRG=s in January 2000 in London, the scheduling of medical papers was far from optimal, as a result of technical communication problems. During the congress, we had many formal and informal contacts with the IASSID and MAMH councils, as well as other SIRG=s. During the general meeting, Bob Davis volunteered to produce a SIRG Newsletter.

3. Activities of the steering committee during the past year

Since the Seattle general meeting, the steering committee, apart from organizing this roundtable in Göteborg, was involved with the following activities.

September 2000: The background papers on healthy ageing were put on the WHO website (www.who.int/mental_health).

October 2000: Dr Bob Schalock was designated by the IASSID Council as the chair of the new IASSID Publication & Research Committee, which has the aim of encouraging research and establishing scientific publications that are in

the interest of the IASSID and advance its purposes. All SIRG=s were asked to contribute to the task of this committee. During the coming Council meeting in September 2001, the issues of a section in the JIDR for each SIRG and an archive for publications will be discussed. We have not yet actively contributed to the committee.

October 2000: Richard Newton, chairman of the MAMH, suggested to together laying out a Richard also asked to cooperate on a distance learning programme. This point has been further discussed during meetings in the Netherlands and in Kassel, Germany, but because of timing problems we have not been involved in these discussions.

October 2000: first Newsletter.

October 2000: Anne Cooper, chairperson of the Mental Health SIRG, proposed a joint roundtable in September 2002 in Glasgow. We have reacted positively; Vee Prasher offered to help with the organisation.

November 2000:

Trevor Parmenter, former chairman of the IASSID, got abridged versions of the consensus statement on sensory impairment and the health targets document, requested by the WHO, to be published together with the background reports on healthy ageing, a Mental Health document and a Quality of Life statement. I do not have further information on this. Trevor further suggested examination of health issues in developing countries as our future contribution for the next WHO-IASSID Work Plan.

March 2001:

Matt Janicki, the new IASSID treasurer, worked out a new system of IASSID membership and financial contributions of SIRG members, together with Bob Davis.

The Journal of Applied Research in Intellectual Disability (JARID) was prepared to publish the background papers on Healthy ageing.

March 2001: the steering committee had a teleconference, where tasks and roles of the steering committee members were agreed upon, to spread the workload and responsibilities. Bob Davis was prepared to combine the posts of secretary and treasurer until the general meeting in Göteborg. He would also continue to produce

framework for levels of evidence that we have in different relevant areas, resulting in systematic plans for research (RCT=s, systematic reviews, qualitative research). We did not yet work out a further plan for this. The Welsh Health Evidence Bulletin on Learning Disabilities (Intellectual Disability), which has been published in February 2001, is an interesting model.

and spread the Newsletter. Monica Björkman would be responsible for the organisation of the venue and finances of the roundtable. Mike Kerr and Vee Prasher agreed to share a role in public relations and a recruitment for the SIRG. Vee Prasher will organize the joint 2002 roundtable together with Anna Cooper. Mike Kerr offered to be our representative on the programme committee of the next IASSID congress, in 2004 in Montpellier, France, which we readily accepted. Further, progress of preparations for the Göteborg roundtable was discussed, as well as a range of practical issues.

May 2001: second Newsletter.

May 2001: We received an invitation for a meeting of the IASSID congress programme committee in Berlin, during a mental health congress. Because Mike Kerr will not participate, we will be represented by Helen Beange and Bob Davis.

June 2001: Some while ago IASSID took the decision to initiate regional scientific meetings to take place in between the world congresses. Patricia Walsh and David Felce announced a European IASSID conference in Dublin for June 12-15, 2002, and asked us, to organize symposia with invited speakers and for practical (time) reasons no call for free papers. We answered that we would have to discuss this at the Göteborg roundtable and that we felt it as restrictive not to have a call for papers.

June 2001: Bob Davis wrote a set of bylaws, as required by the IASSID. These will be discussed at the roundtable.

August 2001: third Newsletter.

Closing remarks

Dear colleagues, as you could read in our Newsletter of last August, the SIRG, urged by the IASSID Council, wants to develop a more formalised structure for the years to come. In this way, we will have to rely less than now on the enthusiastic efforts of only a few individuals.

Nevertheless, I think we have certainly met our aims of formulating first priorities and sharing ideas and results of research, on behalf of better medical care for people with intellectual disabilities. At this last roundtable, we had again dynamic sessions on the themes of treatment of sensory impairment, cerebral visual impairment, the completed epilepsy consensus, and gastro-enterological topics. A list of other topics and ideas are still waiting, just as proposals of the MAMH, other SIRG=s, and IASSID committees for cooperation. As your

The New Chairperson

Dr Mike Kerr is the new Chairperson of the health SIRG. He is a Senior Lecturer at the University of Wales. Dr Kerr also runs clinics specialised epilepsy clinics for adults with intellectual disability. He has been instrumental in setting up the new guidelines for epilepsy management through international collaboration and using a Cochrane style approach

Annual General Meeting Minutes

Novotel, Göteborg Saturday September 19, 2001

Chair: Prof Heleen Evenhuis

Secretary: Assoc Prof Bob Davis

1. Opening and welcome

The chair of the Health SIRG Prof Helen Evenhuis welcomed those in attendance to the AGM of the Health SIRG

Present:

Heleen Evenhuis, Robert Davis, Helen Beange, Vee Prasher, Monica Bjorkman, Arthur Dalton, Ruth Stewart, Mike Kerr, Robyn Wallace, Lyn Stewart, Amin Schlosser, Trudy Arenzt, Sally-Ann Cooper, Jeannie Bormans, Bengt Hagstrom, Jacques Van Splunder, Graham Martin, Mark Scheepers, Matt Janicki

Swedish Members

(2) Apologies

Henny Lantman, Fred Wightman, Terrence Dolan, Olive Webb

(3) Minutes general meeting in Seattle USA, August 2000

Minutes distributed by the internet

parting chairperson, I suggest to keep our original aims in mind and to avoid a too large workload. During the first Leiden roundtable, we had enough sponsor money to invite a colleague from Russia, but unfortunately, our financial possibilities were more limited in later years. In my opinion, invitation of colleagues from less rich countries to come to our meetings should be a stronger priority of our group.

I hope that the SIRG will keep something of its >pioneering=s spirit, which has resulted in a stimulating atmosphere at the roundtables, many good contacts of colleagues and a range of useful products. I thank you very much for your support, confidence and humour during these unruly first five years of our Special Interest Research Group!

Prof Dr Heleen Evenhuis

September 18, 2001

Moved Mike Kerr to accept

Seconded Helen Beange

Carried

(12) Joint roundtable with SIRG on Mental Health in Glasgow, September 11 - 14, 2002

Item 12 was moved higher on the agenda as Professor Cooper needed to leave early for her flight.

Professor Cooper indicated that preparations were well under way for the joint Roundtable in Glasgow with the Psych SIRG. It was planned to have a 3 day meeting with the first day focused on predominantly health orientated issues, the second on issues of concern to both Health-SIRG and Psych-SIRG Members. A draft program had been tabled and while this was not final it was important for planning that we settle on topics and themes very soon. Health and Ageing was a topic that was on the draft program in the first day as the early indications were that this should be included. The discussion at the meeting came to a consensus that issues on ageing may best be dealt with in a joint meeting with the Ageing-SIRG. It was then resolved that the program should continue with the program on health screening/ preventative health and a half day on major life threatening health problems, e.g., nutrition, aspiration, GI disease. The joint day could include a session on medications and intellectual disability.

(4) Chairperson=s Report

Heleen presented a summary of the considerable progress of the Health SIRG over the last 4 years with Papers and Guidelines on Vision and Hearing, Health Targets and Epilepsy amongst a whole host of achievements under her leadership.

(5) Membership and Newsletter

Bob Davis spoke to a document entitled Secretaries report that was forwarded to IASSID council. (Attached)

(6) Membership

A list of Health-SIRG members registered with IASSID was circulated. There were 26 and several names of key SIRG members were missing from that list. It would seem that this was for a range of reasons that included some having corporate membership of IASSIDS, some had membership of other SIRGs within IASSID and others had simply not followed through with commitment.

The following names should be added to the Health SIRG as tabled:

Heleen Evenhuis
Monica Bjorkman
Arthur Dalton
Amin Sclosser
Mark Scheepers
Graham Martin

Structural and organisational requirements of IASSID for SIRG=s

Bob Davis outlined the changes made by IASSID council that outlined the requirements of the individual SIRGs within the organisation. This was to have an agreed set of bylaws to have a minimum of members. A document was presented with the bylaws.

4. Vote on Bylaws

5. Bylaws attached. These had been tabled prior to the meeting. Some minor adjustments motion to that bylaws were accepted was carried.

Moved Mike Kerr

Seconded Helen Beange

Nomination and Election of steering committee for 2001-2002

The following nominations were tabled and elected unopposed.

Mike Kerr	Chair
Helen Beange	Deputy Chair
Bob Davis	Secretary
Vee Prasher	Treasurer

Committee members Robyn Wallace, Monica Bjorkman, Henny Lantman.

It was suggested that previous committee members Olive Webb and Markus Kaski be seconded to continue as members on the committee

(7) Newsletter

Three newsletters were distributed over the last year. Membership response has been encouraging. This duty was taken on by the secretary and has grown to point where a separate committee member needs to direct it.

(8) Financial Report & Financial Plan

A financial statement of the accounts of the Health-SIRG was tabled (document attached)

The document indicates that the expenses of the health SIRG which were essentially for teleconferences and bank fees were covered by the \$US560 raised in membership fees. The SIRG still retains \$US1000 that it was granted from the Geneva conference.

The SIRG will need to raise approx \$US600/year if it is to maintain 3 teleconferences a year assuming the rates remain stable.

(9) Business Arising

Discussion under relevant heading

Appointment of member for programme committee IASSID congress 2004

Mike Kerr was elected as the representative on the program committee with Bob Davis as backup. Bob Davis will attend the initial meeting in Berlin

Future topics and activities

Bob Davis presented the results from the questionnaire circulated to members on topics for future Round tables that showed that the only stand out topic was that of Education of Medical Practitioners and Medical Students. Medications, Preventative health, cerebral palsy, epilepsy, ageing, health issues and syndromes, methods of health care delivery and developing a medical specialty showing about the same level of interest. The feature of the responses was the broad base of interest and if anything it showed that we needed to be eclectic in our material and facilitate individual members developing themes for conferences and Roundtables.

Place and contact person for roundtable 2003
At the request of the new chair, discussion on this topic was postponed to the new committee after the AGM.

Other business

Nil

Closing

Mike Kerr closed the meeting by thanking the out going chair Prof Evenhuis for her tremendous contribution in the development of the health SIRG. The next AGM will be held after the Glasgow roundtable September 2002.

Secretary & Treasury Report 2001

Available on request from Assoc Prof Bob Davis

New Steering Committee & Minutes of Meeting

The new Chairperson elected unanimously was Dr Mike Kerr from Wales, with Dr Helen Beange, Australia, vice Chairperson, Dr Bob Davis to continue as secretary and Dr Vee Prasher accepted treasurer position. A new member elected was Dr Robyn Wallace, Australia. It was hoped that Drs Olive Webb, Henny Lantman and Marcus Kaski would continue as members.



from top right: Monika Borkman. Helen Beange, Bob Davis. Robyn Wallace
from bottom right: Vee Prasher, Heleen Evenhuis, Mike Kerr
absent: Olive Webb, Marcus Kaski, Henny Lantman

Minutes for the Steering Committee of Health SIRG for IASSID

2.00PM B 4.00PM Sept 22nd 2001, Goteborg Novotel

Chair: Dr Mike Kerr

Secretary: Assoc Prof Bob Davis

Present:

Mike Kerr, Bob Davis, Robyn Wallace, Helen Beange, Vee Prasher, Monica Bjorkman

Apologies:

Henny Lantman, Olive Webb, Markus Kaski

Mike Kerr was elected as the chair unopposed at the preceding AGM.

The chair used the meeting to discuss and plan the activities of the SIRG over the coming year.

The issues discussed were:

Defining the Role of the Committee

The Chair felt that we needed to have a clearer understanding of the essential role of the committee and where it was placed within the IASSID framework and in relation to other Medical Groups such as MAMH. In particular its role in defining guidelines on health issues. Vision & Hearing and Epilepsy had progressed well but their path was probably independent of each other and we still had not worked out protocols and pathways for other health issues. It was felt that we could use the experience of the previous activities as a model for others.

Action: Monica and Mike to discuss with MAMH

Membership

The committee clearly felt that membership numbers were well short of what one would expect. Given the significance of health issues and the numbers of medical practitioners around the world involved in the area. The group needed to be multidisciplinary with a health focus. We should be aiming to build the membership to 60. The group still had little involvement from the US and we needed to investigate ways of increasing this. Robyn suggested that we develop a pamphlet specifically on the health SIRG and its activities and that this could be distributed to members to be used to promote the SIRG. Other suggestions included use of the IASSID website

Action: Bob will investigate costs and alternatives to pamphlet.

Progressing Issues Identified this SIRG

The issue Nutrition and related medical problems were seen as important and relatively uncontroversial nutrition issues. Helen suggested that to work up the issue we needed to establish a multidisciplinary group that included the dieticians.

Action: Helen will discuss this further with Lyn Stewart and get back to the committee about this.

2001 Goteborg Conference

Participants had indicated that the Roundtable was a success. There was some concern at the limited numbers but there were a number of factors contributing to this. Importantly the conference budget was in surplus. (\$US1500 - \$US2000) Profit to be distributed 50/50 between Health SI RG and the Swedish Organization SLOHM.

Action: Monica to complete the paperwork and financial statements and Bob and Monica will arrange for distribution of profit to Health SI RG and SLOHM.

2002 Glasgow Conference

The committee felt that preparations for the Glasgow conference had gone very well. We needed however to ensure that health did not get subsumed by the psychiatric issues. The use of medications in ID was the second most popular topic from the recent questionnaire. The conference was well supported with sponsorship and this could be an opportunity to identify and invite key researchers such as Amin and Singh to present on medication.

Action: Vee Prasher to discuss with Anna Cooper and report back.

2003 Conference

Alternative venues were discussed for the 2003

Conference. Given that membership and the engagement of potential members from the US had been identified as a priority the committee felt that it could be an opportunity to run a conference in New York. Mike indicated that he had some contacts and was confident that he could get support for it. Arthur Dalton and Matt Janicki were potential allies in progressing this.

Action: Mike Kerr to discuss with contacts and present at next meeting

Allocation of responsibilities for the coming year:

Mike Kerr	Chair
	I ASSID representative
Bob Davis	Secretary
	Backup I ASSID representative
	Web Site development
	Membership
Vee Prasher	Treasurer
	Co-convener of Joint SI RG in
Glasgow	
Helen Beange	Deputy Chair
Monica Bjorkman	MAMH representative
Olive Webb	
Henny Lantman	
Markus Kaski	
Robyn Wallace	Newsletter

Next Meeting

Action

Teleconference to be organised by Bob in November/ December

Action

Vee and Mike to chase up why they were billed by BT

Combined Health-Psychiatry SI RG Glasgow 2002

Professor Anna Cooper presented for discussion a draft program for this meeting in Glasgow 2002. It was decided that one day would be on Health issues, one on Psychiatric issues and one on the interface. Dr Helen Beange has been invited to deliver the keynote speech on health.

Letters to the editor

We would like to fill this space with your contribution. Please feel free to contact the newsletter with comments on the newsletter itself or on issues that you feel relevant to the group. [Up and coming meeting can also be advertised here.](#) We are keen to see the newsletter as a forum for the views of the membership. We would appreciate submissions either e-mailed directly or submitted as a document. While we will endeavour to include as many as we can, we want to

ensure that the newsletter does not become too unwieldy.

Health-SI RG NEEDS you

If you are interested and have not signed up with the Health-SI RG please do so now.

Use the next page to send us your details.

Please feel free to forward this newsletter to colleagues who might be interested in joining the health-SI RG.

Please Copy and Paste the Whole page & save as (YOURNAME)SI RG.doc and email or fax to robert.davis@med.monash.edu.au as an attachment

Or fax the completed form to +61 3 9564 8330

Application to Join Health SIRG

Please enroll me in the IASSID Health SIRG. My details are given below

First name	
Last name	
Organisation	
Number & Street	
City	
Area Code	
Country	
E-mail Address	
Home Telephone	
Work Telephone	
Fax Number	
Degrees	
Field of Study	
Interests Related to Health 1.	
(Up to 5) 2.	
3.	
4.	
5.	

The Health SIRG of IASSID will contact you regularly with Newsletter and keep you in touch with developments. We welcome your views that can be shared with the group through the list server or be directed through any the committee members.

IASSID will contact you regarding membership. Fees are subject to change but approximate to those quoted earlier in the newsletter. If you are not already a member then you will be asked to choose a category as listed.

Would you indicate whether you would like to enroll on the listserve.

I want don't want to be enlisted on the IASSID-Health Listserver?

November 2001