

# Newsletter Health-SIRG

## IASSID

### Special Interest Research Group (SIRG) for Health Issues May 2001

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#### This is Your Newsletter

This newsletter aims to inform the members of the Health SIRG about the activities of the group, the interests of its members and issues impacting on health of international interest. We hope to use it to plan for meetings and help develop themes on health. We are interested in your views and welcome contributions from the membership. Please contact the editor if you have something to contribute.

It is vital that we know if you change your e-mail address. Please contact us if you do so that we can remain in contact.

## **Profiles of Health SIRG Members**

In the last newsletter I invited members of the Health SIRG to give me a profile so that I could inform the readership of who we are and facilitate the potential for networking that the Health-SIRG should provide. Predictably there was limited response. I have 3 alternatives now, ask again, give up the idea or like all good journalists, what I don't know I make up. (the more sensational the better).

So if you have not written to me giving a short profile of yourself please do!

Fabrizio, Joav and Vee did send me details and I thank them. I have had to edit these to varying degrees but they reflect (as best I could do) the material that was sent to me.

Please contact Fabrizio, Vee or Joav if you have any questions.

**Fabrizio Fea**                      **E-mail**                      **F.FEA-AISE@mclink.it>**

Fabrizio is a neurologist and a forensic doctor. His job is medical director and chief of doctors in a psychiatric clinic close to Rome (private, but it works within the National Health Service). He is a Board member of associations involved in the field of mental retardation (MAMH, IASSID), has assisted in research with the American Association of Mental Retardation (AAMR), was a founding member and first vice president of the Italian Association on Mental Retardation (AIRiM).

Fabrizio is interested in dual diagnosis and involved in rehabilitation and the search for jobs for people with disabilities. In this regard, he established the Italian Association of Supported Employment (AISE) and the World Association of Supported Employment (WASE). He is General Secretary of the European Union of Supported Employment (EUSE), attends conferences and often lectures. He has published reviews on some of his articles and results. Nowadays he works with a very new and important Foundation for the care of the mental ill people in Rome. In 1994 he organised the First International MAMH Congress in Rome and in 1999 the 4th EUSE Conference in Rome.

The issues that he believes to be important are:

- Creation of acceptable standards of care,
- Preventative Health
- Active involvement of People with Intellectual Disability (as much as possible) in health care
- Promotion of the health issues of people with intellectual disability within developing countries

**Joav Merrick**                      **E-mail**                      [jmerrick@aquanet.co.il](mailto:jmerrick@aquanet.co.il)

Joav is a physician and is currently Medical Director of the Division for the Mentally Retarded part of the Ministry of Labour and Social Affairs in Israel. His major research interests within developmental disability are best described as eclectic and include childhood development, family and social influences, epidemiology, epilepsy, aging, visual impairment, disease trends, hospitalization, mortality, health delivery systems and policy issues.

Joav's current activities include:

- Advocating for the establishment of a National Institute for Child Health and Human Development. This institute is to provide a focal point for research, education, training, clinical work, information and leadership in the field of child life, child health, welfare, disability, mental retardation and human development on a national coordinated level.
- Expenditure studies on the state budget to services for children, the disabled and the mentally retarded in Israel.
- Establishing Israeli National Database's on:
  - Epilepsy.
  - Blindness and Visual Impairment
  - Cerebral Palsy
  - Persons with Mental Retardation

Joav has used alliances with other health services and universities within Israel to develop research into the following problems in people with intellectual disability:

Physical injury, assistive technology, trends in body weight and height, hepatitis A, B, C and HIV, Helicobacter infections, aging, psychiatric care, psychiatric hospitalization, challenging behavior, usage of psychotropic medication, general drug usage, dental health profile, cause of deaths, trends in mortality, trends in emergency room visits, gynaecologic problems, abuse and neglect, usage of wheel-chairs in the institutions and the list goes on.

**Dr. Vee Prasher**                      **Email address**                      [vprasher@compuserve.com](mailto:vprasher@compuserve.com)

Vee is a Consultant Psychiatrist and Senior Clinical Lecturer at the University of Birmingham. Birmingham is part of the West Midlands which is the central region of England.

Vee has worked in the field of learning disabilities for the last 10 years having learnt his skills and developed enthusiasm for the academic side of learning disability under the guidance of Professor John Corbett, an eminent Professor who sadly retired last year.

During the last 10 years Vee has completed 3 post doctorate degrees;

- (1) Masters and Medical Science, looking at the role of visual evoked potentials in the diagnosis of dementia in adults with Down's syndrome,

- (2) Doctorate of Medicine looking at the epidemiology of health morbidity in adults with Down's syndrome
- (3) (3) Doctorate of Philosophy completed last year, investigating a number of biological markers as measures of Alzheimer's disease.

He has published a number of papers previously which are listed on the website [www.prasher.co.uk](http://www.prasher.co.uk).

At present as well as having medical responsibility for a large catchment area of people with learning disability, he continues his research interests. He has just completed a double blind placebo controlled trial of Aricept in people with Down's syndrome, and at present is participating in an international study of the role of Vitamin E in the prevention of Alzheimer's disease in people with learning disability which is headed by Dr. Arthur Dalton from New York.

He tells me that he is more than happy to discuss issues with other members of SIRG and can be contacted by e-mail.

### **Teleconference of the Health-SIRG Steering Committee**

After six months of negotiation we finally managed to organise a teleconference for the steering committee of the Health-SIRG. The main problem that we had to overcome was the expense. Fortunately we were able to identify a cheaper teleconference provider and IASSID has allocated sufficient funds to cover the cost of this. The difficulties in doing this have emphasised the need to have some operational funding available for the Health-SIRG's activities.

### **Executive and Organisation**

The meeting discussed the need to develop a more formal and democratic structure. The Health-SIRG has grown from an informal collaboration of like-minded individuals and successfully run its own round tables and drawn up management guidelines. It was felt that now was the time to move forward. IASSID has indicated that it requires the interest groups to meet regularly and to elect their executive. The round table at Göteborg was seen as the best time to start off this process. In the meantime Heleen Evenhuis has agreed to continue in the role as chairperson, Helen Beange as the deputy and Bob Davis will continue as secretary/treasurer. Monica Björkman will coordinate the Göteborg round table.

## **Göteborg Roundtable**

The program for the Göteborg Roundtable will include four ½ day seminars on the following topics: interventions in hearing and visual impairment, cerebro-visual impairment, helicobacter screening/nutrition and epilepsy. We have set aside 2 hours of the program for a general meeting of SIRG and a further 2 hours for discussion and development by the membership of the program for the next round table. The committee has decided to circulate a questionnaire to the members to determine the priority for issues to be discussed at this meeting. The results will be presented at Göteborg. The program for Göteborg will be circulated shortly.

## **Round Table 2002**

The round table for 2002 is planned for Glasgow from 11<sup>th</sup> –13<sup>th</sup> September and will be a joint meeting with the Psych-SIRG of IASSID. Prof. Anna Cooper and some of the UK colleagues have kindly offered to coordinate this event. We believe that this could be used to develop issues common to both groups as well as those unique to both. The conference in Göteborg will involve discussion on the program for 2002.

## **IASSID Conference 2004**

The meeting discussed the concerns that some members had expressed with the grouping of presentations about health at the Seattle conference. It was felt that the Health-SIRG needed to be a bit more proactive. Mike Kerr works in close proximity to David Felce who is in charge of the academic program for 2004 and has offered to represent the Health-SIRG in discussions on the programming.

## **Finances and Health SIRG**

The continuing viability of the Health-SIRG means that it will need to be self-supporting financially. We have therefore decided to look at our financial projections for the coming year to help us plan around the new financial arrangements suggested by IASSID. The SIRG's are funded \$US5 from each membership fee where that member indicates that the Health-SIRG is their primary special interest group. As well as this we can generate an assessment fee that the SIRG member pays to IASSID and all of this money is completely passed on to the SIRG.

The cost to the individual member will be determined by the category of IASSID membership eg (calculated from fees current Jan 2000)

SIRG member only \$US25 to IASSID plus \$US20 assessment (Total \$US45)

IASSID with journal \$US75 to IASSID plus \$US20 assessment (Total \$US95)

In both cases \$US25 goes to the SIRG with IASSID keeping \$20 as administrative fees. The individual SIRG's can levy their own assessment. One of the issues that the membership needs to decide in Göteborg is what do we charge our membership or how else do we continue funding our activities

## **News from Around the World**

This section will be used to inform people of what is happening in Developmental Disability Health around the world. If you have any news please send it to me. I would be really interested in any reports from conferences (local or international). Any news on the development of services, research initiatives, funding, awards, impending marriages, gossip or anything that you think the readership might be interested in.

### **USA**

Those of you who are on the listserv “MEDICAL-DD@LISTSERV.NODAK.EDU” will be aware of Phil May’s efforts to setup an organisation of medical practitioners in the USA. Philip administrates one of the best listservs in Developmental Disability Health providing active and relevant discussion on medical issues and useful information. A recent posting encouraged the readers to check out the “Special Olympics” web site contained some great papers on health and health issues. I would urge you all to access it at the web site address <http://www.SpecialOlympics.org>

### **Australia**

The Centre for Developmental Disability Health Victoria (CDDHV) is organising Australia’s first National Seminar for Health Professionals on Developmental Disability from November 8<sup>th</sup>-9<sup>th</sup> 2001 in Melbourne Victoria . The Seminar has international key note speakers has invited Professor Sally Ann Cooper (Psychiatry) and Professor Pasquale Accardo, M.D. (Paediatrics), New York Medical College. This year the CDDHV launched its first distance education subject in Developmental Disability Health entitled “Introduction to Developmental Disability” with the first group commencing in August 2001. The subject targets primary care physicians with an interest in developmental disability health and aims to give the participants a basic understanding of the issues. It will be complemented with a management subject and will ,we hope form, the framework of a graduate diploma in developmental disability health. The course will be delivered using the distance education expertise of the Monash University and the Department of General Practice. Both have an international reputations for the high quality of their distance education programs. Details of the subject can be found at the CDDHV’s web site address <http://www.med.monash.edu.au/general-practice/units/cddh>. The conference program is included in a file attached with this newsletter and can be read using adobe.

### **Canada**

I was very interested to see the contribution on a web site (<http://www.psychiatry.med.uwo.ca/ddp/bulletins/01marbul.htm>) by Adam Rapaport, a second year Canadian Medical student. It is heartening to see younger colleagues being inspired to work in the area. Adam e-mailed me to let me know how he got involved. He tells me that his interest dates from a course in his first 2 years at medical school “Health and Illness in the Community (HIC)”

The goal of this course is to make medical students aware that medicine is not only interested in illness, but also health and its promotion. Students had to choose an organisation to partner up with, and create a project about an aspect of health care in the community. Adam chose an organisation caring for people with Down syndrome. The project has fostered a continuing interest in the field and demonstrates the advantages of engaging younger medical students in the issues around people with developmental disabilities. The web site <http://www.psychiatry.med.uwo.ca/ddp> itself is well worth a visit as it contains a wealth of material. You will see that Dr Elspeth Bradley and her University of Western Ontario colleagues have been very active in their corner of the world.

### **IASSID-Health List**

In the last newsletter I indicated that we were setting up an IASSID-Health listserv as a means of communication within the group. The setting up of this list was complicated by a change in the configuration of the computer networks at Monash university. The technicians here took months to finally work it out so effectively this has only been operational for the last month. Do people want to use this as a means of keeping in touch? We will run it over the next few months and if there is sufficient response we will maintain it. If not then there is probably no point in continuing on with it.

### **Membership of the Health-SIRG**

An application form for the health-SIRG accompanied our first newsletter . So far we have thirty applicants and thereby qualify to be represented on IASSID council. There are a few names missing that I would expect to be on that list so if you haven't forwarded it to me please use the attached application and forward it to the manager of CDDHV Jenny Morrison at [jenny.morrison@med.monash.edu.au](mailto:jenny.morrison@med.monash.edu.au).

The field of study of the members of the group include: health, ophthalmology, psychiatry, social work, rehabilitation, medical education, psychology, paediatrics, neurology, dentistry, public health and epidemiology. Some of the more common areas of interest included Down syndrome, psychiatry, Alzheimer's disease, epilepsy, ageing, challenging behaviours, communication, health promotion and policy, primary health care, medical education and epidemiology of developmental disability.

Sharing information about ourselves is a way of building the strength of a group. Many of the issues we face in our individual countries are similar. I would appreciate it if SIRG members could help me build some links by forwarding to me details about themselves, their area of interest, activities that would be of interest to other SIRG members etc.

## **RECENT PUBLICATIONS LIST**

**submitted by Dr Vee Prasher**

Vee has agreed to submit a list of recent publications in developmental disability medicine worthy of review to the newsletter with specific themes. We hope that you find these useful.

### **DOWN SYNDROME**

1. **Authors:**  
Book L. Hart A. Black J. Feolo M. Zone JJ. Neuhausen SL.  
**Title:**  
Prevalence and clinical characteristics of celiac disease in Downs syndrome in a U.S. study.  
**Source:**  
American Journal of Medical Genetics. Vol 98(1) (pp 70-74), 2001.
2. **Authors:**  
Hennequin et al  
**Title:**  
Prevalence of oral health problems in a group of individuals with Down syndrome in France.  
**Source:**  
Developmental Medicine & Child Neurology. Vol 42(10) (pp 691-698) 2000.
3. **Authors:**  
Ghaziuddin M.  
**Title:**  
Autism in Down's syndrome: A family history study.  
**Source:**  
Journal of Intellectual Disability Research. Vol 44(5) (pp 562-566), 2000.
4. **Authors:**  
Jacobsen FS. Hansson G.  
**Title:**  
Orthopaedic disorders in Down's syndrome.  
**Source:**  
Current Orthopaedics. Vol 14(3) (pp 215-222), 2000.
5. **Authors:**  
Chapman RS. Hesketh LJ.  
**Title:**  
Behavioral phenotype of individuals with down syndrome.  
**Source:**  
Mental Retardation & Developmental Disabilities Research Reviews.

6. **Authors:**  
Merrick J. Shapira J.  
**Title:**  
Preventive dental health for persons with Down syndrome.  
**Source:**  
International Journal of Adolescent Medicine & Health. Vol 12(1) (pp 81-84),2000.
7. **Authors:**  
Merrick J.  
**Title:**  
Obesity in persons with Down syndrome.  
**Source:**  
International Journal of Adolescent Medicine & Health. Vol 12(1) (pp 69-74),2000.
8. **Authors:**  
Merrick J.  
**Title:**  
Medical concerns in Down syndrome.  
**Source:**  
International Journal of Adolescent Medicine & Health. Vol 12(1) (pp 43-51),2000.
9. **Authors:**  
Tyler CV Jr. Snyder CW. Zyzanski S.  
**Title:**  
Screening for osteoporosis in community-dwelling adults with mental retardation.  
**Source:**  
Mental Retardation. 38(4):316-21, 2000 Aug.
10. **Authors:**  
Taggard DA. Menezes AH. Ryken TC.  
**Title:**  
Treatment of Down syndrome-associated craniovertebral junction abnormalities.  
**Source:**  
Journal of Neurosurgery. 93(2 Suppl):205-13, 2000 Oct.
11. **Authors:**  
Chapman RS. Hesketh LJ.  
**Title:**  
Behavioral phenotype of individuals with Down Syndrome. [Review] [146 refs]  
**Source:**  
Mental Retardation & Developmental Disabilities Research Reviews. (2):84-95, 2000.

## **LETTERS TO THE EDITOR**

I 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. I am keen to see the newsletter as a forum for the views of the membership. I would appreciate submissions either e-mailed directly or submitted as a document. While I will endeavour to include as many as I can, I want to ensure that the newsletter does not become too unwieldy.

## **Health-SIRG NEEDS you**

If you are interested and have not signed up with the Health-SIRG 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-SIRG.

Please Copy and Past the Whole page & save as (YOURNAME)SIRG.doc

and send to ([robert.davis@med.monash.edu.au](mailto:robert.davis@med.monash.edu.au)) as an attachment

Or fax the completed form to 61 3 9564 8330

## Application to Join Health SIRG

Can you please enrol 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.

Can you indicate whether you would like to enrol on the listserver.

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

**Indicate your preference by deleting your non-preferred statement.**