

## **Committees of the International Angelman Syndrome Organisation**

### **Executive Committee:**

#### President - Mrs. Simone Kennedy - Australia

Simone Kennedy is the mother of three children: Andrew (AS del+, b. 1988), Emma (b. 1990) and Renee (b. 1994). Simone is currently the President of the Australian Angelman Syndrome Association, a position she has held since 1995. She was one of 3 parents instrumental in the formation of the Australian Angelman Syndrome Association in 1993.

Simone is often the first contact many new AS families have in Australia and with husband Kevin, produces and edits the Australian newsletter. Simone was a member of the first meeting of the IASO in Ottawa, Canada in 1998 and was elected to the first IASO board. She works part-time as a primary school teacher and lives in Engadine, Sydney, Australia.

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#### Vice-President - Mr. Heikki Taimio - Finland

Heikki Taimio is father of two girls - Liisa (AS, b. 1990) and Annina (b. 1986). He was the first President of the Finnish Angelman Syndrome Society (FASS) in 1997-98 and is now the Vice-President. He was a member of the IASO Working Group which was set up at the ASF Conference in Seattle, July 1997, and which prepared the first meeting of the IASO in Ottawa, Canada, in August, 1998. He has served as the Vice-President of the IASO since that meeting. Heikki also chaired the National Organising Committee of the 1st World Conference of the IASO in Tampere, Finland, from 4-8 July, 2000. He is a university economist by profession and lives in Joensuu, eastern Finland.

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#### Mrs. Vibeke Nicolaisen - Denmark

Vibeke Nicolaisen is the mother of three: Lulu (b. 1985), Mark (del +, b. 1988) and Katryn (b. 1994). She is married to Kris, who is President of the Danish Angelman Association. She is newsletter editor and webmaster for the Danish AS website and in her spare time she is secretary and mind-reader to Kris.

Vibeke took the first initiative for the establishment of the Danish Angelman Association in 1994 (the Association was founded in 1995), and she chaired the Programme Committee of the 1st World Conference of the IASO. She is a correspondent by profession and lives in the countryside, 60 km south of Copenhagen, Denmark.

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#### Mrs. Sally Walburn - U.K.

Sally Walburn is mother of two girls: Rachel (b.1985) and Laura (b.1987) and one son, Matthew (b. 1991 del+). She is wife and Company Secretary to Ken, who is also a trustee of ASSERT. In her spare time, she runs a local support group for families of children with special needs and is actively involved in local issues. Sally is the Chairperson of ASSERT (Angelman Syndrome Support and Education Research Trust) in the UK. She takes an active role on the telephone support line, writes and edits the ASSERT Report, and has recently chaired the First National ASSERT Conference in September, 2000. Sally was a member of the first meeting of the of the IASO in Ottawa, Canada, in August, 1998. She lives in Basildon in Essex (near London).

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### **Scientific Committee:**

#### Dr. Arabella Smith, Chair - Australia

Arabella (Ellie) Smith is Senior Staff Specialist and Associate Head at the Department of Cytogenetics of the New Children's Hospital, Westmead, Australia.

Following graduation Ellie undertook a lengthy 15 year period of part-time work (to accommodate family - 4 daughters) at the (then) Oliver Latham Laboratory, NSW Department of Health (1970-1985). The work here firstly involved the newborn screening program and then from 1979, cytogenetics. Postgraduate qualifications were obtained in the UK in 1988 with the Diploma in Clinical Cytogenetics and Molecular Genetics (DipRCPath), Human Genetics Society of Australasia Certification in Clinical Cytogenetics in 1989 (HGSACC) and the Royal College of Pathologists, Australasia in 1990 (FRCPA).

Major research interests, including two 5-year NH&MRC Grants, have involved Prader-Willi Syndrome (PWS) and Angelman Syndrome (AS). She has over 100 original publications in reputable medical journals. Ellie currently works as Senior Staff Specialist in Cytogenetics at the New Children's Hospital, Westmead and is particularly responsible for the oncology and FISH (new technology) sections. She is honorary Professional Adviser for the Australian PWS Association, Board Member of the International PWS Organisation, Professional Consultant for the ASA (Angelman Syndrome Association of Australia), on the Board of the IASO (International Angelman Syndrome Organisation) and Friend of the Microscopical Society of Australia (Vice-President 1993-1998). Ellie is the founder and a Past-President of the Australasian Society of Cytogeneticists and a Past-President of the Medical Women's Society of NSW. She was Convenor for Health for National Council of Women 1992-1995, 1997-1998 and Adviser on Health and Nutrition 1997-1999. As of now, she has 5 grandchildren.

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#### Dr. Stewart Boyd - UK

Stewart Boyd, Consultant Clinical Neurophysiologist at Great Ormond Street Hospital for Children, London. I have worked in this Dept since 1982, including a stint as head of Dept between 1988 and 1999. I have a long-standing interest in the EEG and clinical neurophysiology of AS. We are currently planning research into the communication disorder using mainly event-related potential recordings. I am also involved in a large paediatric epilepsy programme, and this is clearly relevant to some aspects of AS. However, I do not have my own patients, but depend on referrals from clinicians for investigation.

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#### Dr. Bernard Dan - Belgium

Bernard Dan studied medicine at the Free University of Brussels and did part of his training in paediatric neurology at Great Ormond Street Hospital in London, where he developed an interest in Angelman syndrome. He helped Belgian families to set up an Angelman syndrome support group, and organised the First National Symposium on Angelman Syndrome in Belgium in 1997.

Bernard is currently the head of the department of neurology at the University Children's Hospital in Brussels and professor of developmental neurology at the Free University of Brussels. His research focuses on motor strategies in movement disorders including Angelman syndrome.

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#### Dr. Charles Williams - USA

Charles Williams, M.D. is a Professor of Pediatrics and Genetics, Department of Pediatrics. He is a native Floridian and has had a longstanding career at the University of Florida as he joined the university in 1978. He is a board-certified pediatrician and clinical geneticist and has a special interest in neurogenetic syndromes and related conditions.

The main focus of his research career has been in the study of Angelman Syndrome. Since 1982 he has published many papers on the genetic and medical aspects of

Angelman Syndrome. In 1987 he was instrumental in founding the USA Angelman Research Foundation which subsequently evolved into the USA Angelman Syndrome Foundation.

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***Communications Committee:***

To be completed soon.

***Fundraising Committee:***

To be completed soon.