

**CONFERENCE  
SUMMARY**



**INTERNATIONAL  
SYMPOSIUM  
RUGBY • UNITED KINGDOM  
23rd • 24th • 25th • 26th • October**

# Acknowledgements

The Ann Conroy Trust wishes to thank the many organisations and individuals who have contributed to making this event possible, including the Society of British Neurological Surgeons, the European Spine Society, the University of Birmingham and the Headmaster and staff of Rugby School.

## INTERNATIONAL ADVISORS

*Ulrich Batzdorf*, USA  
*Thomas Milhorat*, USA  
*Edward Oldfield*, USA  
*Tatsuya Nagashima*, Japan  
*Dieter Grob*, Switzerland  
*Jerry Oakes*, USA

*Harold Rekate*, USA  
*Jorg Klekamp*, Germany  
*Guy Rouleau*, Canada  
*Marcus Stoodley*, Australia  
*Alfred Aschoff*, Germany  
*Concezio Di Rocco*, Italy

## UK FACULTY

*Graham Flint*, The Queen Elizabeth Hospital, Birmingham  
*Marek Czosnyka*, University of Cambridge  
*Wagih El Masry*, Midlands Centre for Spinal Injuries, Oswestry  
*Clare Rusbridge*, Stone Lion Veterinary Centre, London  
*Spyros Sgouros*, Children's Hospital, Birmingham  
*Tim Piggot*, The Walton Centre for Neurology and Neurosurgery, Liverpool  
*Sid Marks*, The James Cook University Hospital, Middlesbrough  
*Robert Battersby*, The Royal Hallamshire Hospital, Sheffield

*Robert Redfern*, Morriston Hospital, Swansea  
*Andrew Brodbelt*, The Walton Centre for Neurology and Neurosurgery, Liverpool  
*Dominic Thompson*, Great Ormond Street Children's Hospital, London  
*Carl Hardwidge*, Hurstwood Park Neurological Centre, Haywards Heath  
*Conor Mallucci*, The Walton Centre for Neurology and Neurosurgery, Liverpool  
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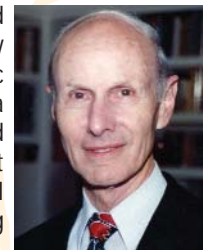




# Invited Speakers & International Advisors

## **ULRICH BATZDORF**

Dr Batzdorf completed his neurosurgical residency training at the University of California, Los Angeles (UCLA) in 1966, and has been on the neurosurgical faculty at UCLA since then. His initial research was on malignant brain tumors and pituitary tumors. Concurrently he developed an interest in surgery of the spine and spinal cord, especially in cervical spondylotic myelopathy. For the past 20 years, his major focus has been on syringomyelia and Chiari malformation. Syringomyelia, a multi-authored book that he edited, was published in 1991; Syringomyelia, Current Concepts, co-edited with Tamaki and Nagashima, appeared in 2001. Dr Batzdorf is on the Medical Advisory Board of the American Syringomyelia Alliance Project (ASAP). In 2005, he was recipient of the Meritorious Service Award of the American Association of Neurological Surgeons/Congress of Neurological Surgeons Section on Disorders of the Spine and Peripheral Nerves. He was a founding member and director of the UCLA Joint Orthopaedic-Neurosurgical Comprehensive Spine Center.



## **THOMAS MILHORAT**

Thomas H. Milhorat, M.D. is Professor and Chairman of Neurosurgery at North Shore University Hospital and Long Island Jewish (LIJ) Medical Center, Director of the Harvey Cushing Institutes of Neuroscience, and Director and Founder of The Chiari Institute. The success of The Chiari Institute as a model for designing multidisciplinary, disease-focused neuroscience programs led the family of Dr. Harvey Cushing to lend his name and support the development of 12 institutes which Dr. Milhorat now heads. Prior to joining the North Shore-LIJ Health System in 2002, Dr. Milhorat served as Professor and Chairman of Neurosurgery at the State University of New York (SUNY) Health Science Center at Brooklyn, Neurosurgeon-in-Chief of Kings County Hospital Center, and Chairman of Neurosurgery at the Long Island College Hospital where he established a Chiari Center. From 1971 - 1982, Dr. Milhorat was Chairman of Neurosurgery at the Children's Hospital National Medical Center in Washington, D.C., and Professor of Neurosurgery and Professor of Child Health and Development at George Washington University. Prior to that, he served for five years as Clinical Associate and Assistant Neurosurgeon at the National Institutes of Health where his investigations on hydrocephalus and circulation of the cerebrospinal fluid led to landmark articles in Science, The New England Journal of Medicine, and the Journal of Neurosurgery. Dr. Milhorat's current research interests are focused on Chiari malformations, syringomyelia, hereditary disorders of connective tissue, tethered cord syndrome, and pseudotumor cerebri.



## **EDWARD OLDFIELD**

Professor of neurosurgery at University of Virginia, Dr Oldfield was, until very recently, Chief, Surgical Neurology Branch, National Institutes of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, MD, USA. Dr. Oldfield received his M.D. from the University of Kentucky Medical School, training in general surgery and neurosurgery at Vanderbilt University and in neurology at the National Hospital for Nervous Disease, London, England. At NIH he led a laboratory and clinical research effort in neurosurgery. His interests include brain and pituitary tumors, syringomyelia, the development of new drug delivery techniques for the central nervous system, neural transplantation and regeneration, Von Hippel-Lindau disease, and certain types of vascular disorders of the central nervous system, particularly arteriovenous malformations affecting the spinal cord, dural arteriovenous fistulas, and the pathophysiology and treatment of cerebral vasospasm. In addition to his clinical interests, he has sought to use new information and techniques of basic science to develop new treatment approaches for disorders of the brain and spinal cord. Dr. Oldfield is former chairman of the Editorial Board of the Journal of Neurosurgery. In 1995 he was awarded the Grass Medal from the Society of Neurological Surgeons and in 1999 he received the Farber Award of the American Association of Neurology Surgeons.



## **JORG KLEKAMP**

Dr. Klekamp graduated from Hanover medical school in 1984. He received his doctor degree the same year with a thesis on brain anatomy. He continued his anatomical studies between 1986 and 1988, at the department of neuropathology of the University of Sydney, with a project on the anatomical development of the human brain. In 1989 he began his neurosurgical training, at the Nordstadt Hospital Hanover, where he stayed until 2003. He became a certified neurosurgeon in 1994. His major interests include scientific and clinical work on syringomyelia and malformations and tumours of the spinal canal and craniocervical junction. He performed experimental and clinical work on syringomyelia under supervision of Ulrich Batzdorf in Los Angeles, from 1993 to 1995. He received the Wilhelm Tönnis prize of the German Society of Neurosurgery in 1995, for work on syringomyelia. His thesis on the pathophysiology and treatment of syringomyelia was accepted by the medical school of Hanover in 1999. He became associate Professor of Neurosurgery in 2002 and, since 2004, has been working as a neurosurgeon at the Christliche Krankenhaus, Quakenbrück, Germany. He published a monograph on Syringomyelia (Syringomyelia - Diagnosis and Treatment) in 2001 and of a textbook on surgery of spinal tumours in 2007.



**TATSUYA NAGASHIMA**

Dr. Nagashima received his M.D. from Kobe University Medical School in 1977, training in neurosurgery at Kobe University and in neurology at Kyushu University. He completed his neurosurgical training in 1984. He was a visiting research fellow at Laboratory of Neurosciences, NIA, NIH (Bethesda) from 1985 to 1987, then was a lecturer in neurosurgery of Kobe University. He was a member of the research committee on Syringomyelia organized by Japanese Ministry of Health, Labor and Welfare in 1994-1998. Dr. Tamaki and he organized International Symposium "Syringomyelia 2000" in Kobe. The proceedings of the symposium were published as "Syringomyelia: Current Concept in Pathogenesis and Management" in 2001, co-edited with Dr. Batzdorf. Since June 2001, he has been the Chief of the Department of Neurosurgery, Kobe Children's Hospital and Clinical Professor, Kobe University School of Medicine. His current interest includes syringomyelia of children, spinal dysraphism, pediatric brain tumors and abusive head trauma.



**JERRY OAKES**

W Jerry Oakes, MD, is professor of neurosurgery and pediatrics at University of Alabama at Birmingham and chief of pediatric neurosurgery at the Children's Hospital of Alabama. In addition to being chosen as holder of the Dan L. Hendley Endowed Chair in Pediatric Neurosurgery, he also recently has been named editor-in-chief of Pediatric Neurosurgery, the official journal of the American Society of Pediatric Neurosurgeons. He earned his medical degree from Duke University in 1972 and completed postgraduate studies at Duke University Medical Center, Toronto General Hospital, and in London, England. He served on the Duke faculty prior to joining UAB and is board certified in neurosurgery and pediatric neurosurgery.



**MARCUS STOODLEY**

After completing his medical training at the University of Queensland in Australia, Dr Stoodley went on to train in neurosurgery in Perth and Adelaide. His PhD at the University of Adelaide was awarded for experimental studies of the pathophysiology of syringomyelia. He then undertook fellowship training in neurovascular surgery at the University of Chicago and Stanford University, before returning to Australia to his current position at the University of New South Wales and Prince of Wales Hospital. He continues his clinical and research interest in syringomyelia, with a focus on fluid flow and cellular responses to syrinx formation. Dr Stoodley also has a research interest in the molecular biology of arteriovenous malformations and their response to radiosurgery.



**MAREK CZOSNYKA**

Marek Czosnyka obtained his Phd and DSc in Biomedical Engineering in Warsaw. He is currently reader in Brain Physics and Director of Neurosurgical Physics at the University of Cambridge, UK. He is also Associate Professor at Warsaw University of Technology, Faculty of Electronics. His principal area of research is cerebrospinal fluid dynamics (hydrocephalus, BIH, syringomyelia), cerebral blood flow and its regulation (head trauma, stroke, hydrocephalus, subarachnoid hemorrhage, experimental models), multi-modal bedside monitoring in neuro-intensive care (head trauma, poor grade SAH, stroke), mathematical modeling of cerebrospinal dynamics, asymmetry of cerebral blood flow, its regulation and cerebrospinal dynamics.



**CLARE RUSBRIDGE**

Clare Rusbridge started her veterinary training at the University of Glasgow and graduated in 1991. In 1993 she joined the Royal Veterinary College, completing a BSAVA/Petsavers residency in Neurology under Simon Wheeler and then spent one year as a Staff Clinician in Neurology. In 1996 she was board-certified by the European College of Veterinary Neurology. Since August 1997 she has operated a neurology referral service at the Stone Lion Veterinary Referral Centre in Wimbledon, gaining Royal College of Veterinary Surgeons Specialist status in 1999. She came across her first "scratching Cavalier" (Beau) in 1995 when a resident at the Royal College of Veterinary Surgeons. It wasn't until two years later when spinal MRI was available for animals that she determined that he had syringomyelia, secondary to a Chiari-like malformation. It rapidly became apparent that this condition was not as rare as once thought and over the past 10 years Clare continued to research this disease focusing on the genetics, pathogenesis and treatment. Her other professional interests include epilepsy and feline neurology, in particular familial trigeminal neuralgia in Burmese cats.



**DOMINIC MARINO**

Dr Dominic J Marino graduated with honors from Auburn University in Alabama, where he received both his Bachelor of Science and Doctor of Veterinary Medicine degrees. He completed a one-year internship in small animal medicine and surgery at the University of Georgia and a three-year comprehensive residency in small animal orthopedic, soft tissue and neurosurgery at the Animal Medical Center in New York City. Dr. Marino was honored with both the Martin and Beatrice Weiser Outstanding Research Award and the North Shore Animal League Petering Scholarship Award during his residency. He is board certified by the American College of Veterinary Surgeons and is the former head of Orthopedic/Neurosurgery service at the Animal Medical Center in New York City. Dr Marino has published many scientific articles, and authored chapters in veterinary medical textbooks.





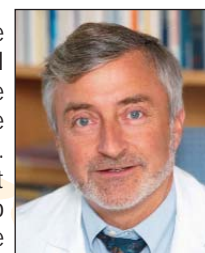
**GRAHAM FLINT,**

A neurosurgeon at The Queen Elizabeth Hospital in Birmingham UK, Graham runs the syringomyelia service established there by the late Bernard Williams. In the early part of his consultant career Graham specialised in treating a variety of spinal disorders but has since developed, via his inherited interest in syringomyelia, a practice dealing principally with various disorders of CSF circulation. In 2005 he brought together a group of UK based neurosurgeons with an interest in syringomyelia. Graham sees Syringomyelia 2007 as the natural progression of this project, with the assembly of an international group, encompassing a variety of interested disciplines, who can discuss and share their knowledge, understanding and uncertainties about syringomyelia and its related conditions.



**DIETER GROB**

Dr. Grob graduated at the medical school of the University of Zürich in 1975. After specialising in general orthopaedics he was trained in spine surgery with Prof. Fritz Magerl, learning innovative techniques such as transarticular atlanto-axial screw fixation, translaminar fixation in the lumbar spine and direct screw fixation of the fractured dens, as well as routine transpedicular fixation techniques in fracture fixation and degenerative conditions of the cervical and lumbar spine. He completed training in surgical treatment of spine pathologies in Zürich, at the Schulthess Hospital, with Prof H. Scheier. Since 1987 Dr. Grob has been the head of spine surgery at the Schulthess Hospital and under his guidance the department has grown into a modern centre with more than 1200 interventions per year, headed now by one neurosurgeon and two orthopaedic surgeons. In the recent years, Dr Grob's main interest has focused on quality control and clinical outcome studies. Dr. Grob is currently president of the International Society of the Study of the Lumbar Spine (ISSLS).



**HAROLD REKATE**

Dr. Rekate obtained his MD from the Medical College of Virginia in Richmond. He trained in neurosurgery at the University Hospitals of Cleveland of Case Western Reserve University. After completing residency he joined the faculty as the chief of pediatric neurosurgery. In 1985 he was recruited by the Barrow Neurologic Institute in Phoenix and became the first paediatric neurosurgeon in Arizona, where he is currently chairman of paediatric neurosciences. While at Case Dr Rekate developed a close relationship with the Institute of Technology and became Adjunct Professor of Systems and Design Engineering. Development of a mathematical model of ventricular volume regulation, using computer simulation, led to innovative strategies for the management of a wide variety of previously enigmatic conditions of cerebrospinal fluid dynamics, with over 50 related publications. He received the prestigious Pudenz Award for Excellence in CSF Research in 1992. Dr. Rekate has served as the Chairman of the Joint Section on Pediatric Neurologic Surgery of the AANS and CNS (1993-1995), president of the International Society of Pediatric Neurosurgery (1999-2000), and President of the American Society for Pediatric Neurosurgeons (2000-2002). He currently serves as the Chairman of the Editorial Board for the Journal of Neurosurgery, Pediatrics.



**GUY ROULEAU**

Guy A. Rouleau, MD, PhD, FRCP(C) is a Professor in the Department of Medicine at the Université de Montréal. He is at the head of the Research Centre at Saint-Justine Hospital and the Centre for excellence in neuromics at the Université de Montréal. Over the last 20 years his work has focused on understanding the genetic basis for diseases of the brain. Specifically, he has mapped over 20 disease loci and significantly contributed to the identification of over 10 genes causing diseases, as well as to a better understanding of the pathogenesis of various diseases. He researches numerous neurological and psychiatric diseases, including amyotrophic lateral sclerosis, stroke, familial aneurysms, cavernous angiomas, epilepsy, spinocerebellar ataxia, spastic paraplegia, autism, Tourette syndrome, restless legs syndrome, schizophrenia and bipolar disorder. His laboratory endeavours to understand the pathogenesis of amyotrophic lateral sclerosis, oculopharyngeal muscular dystrophy and CAG repeat disorders, using cell and animal models.



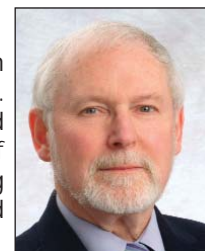
**HELEN WILLIAMS**

Helen Williams is a general practitioner in London, England. Her father was Bernard Williams. Helen's interest in the subject of syringomyelia developed out of an interest in clinical ultrasound. She has applied ideas that she learned from her father to her own. This leads to the proposal that Chiari related syringomyelia and spina bifida are caused by posterior fossa hypoplasia. The idea of posterior fossa hypoplasia as a primary pathology arose in 1997 when Helen saw an ultrasound image of the crowded posterior fossa of a spina bifida fetus. She has since examined the existing evidence, and developed a unifying hypothesis for all forms of syringomyelia. These ideas were included in the essay entitled "An essay concerning the pathogenesis of hydrocephalus" which was awarded the Casey Holter memorial essay prize for 2007.



**ROY WELLER**

Following research and clinical posts in London and New York, Roy Weller was appointed Professor of Neuropathology in the University of Southampton School of Medicine and Consultant Neuropathologist to the Wessex Neurological Centre. Early research work on the pathology of acute hydrocephalus in humans and experimental models of hydrocephalus and syringomyelia progressed to the study of the anatomy and pathology of CSF drainage pathways and to the role of lymphatic drainage of the brain in immunological reactions in the brain. More recently he has concentrated on defining the perivascular pathways by which interstitial fluid drains from the brain and how such pathways are impaired by amyloid deposits in cerebral amyloid angiopathy in Alzheimer's disease.



# Programme at a Glance

## Tuesday 23rd October

- 12.00: Registration, Conference Office, Temple Speech Room, Rugby School
- 15.00: Tour of Rugby School
- 18.00: Welcome reception, Temple Speech Room (exhibition hall), Rugby School
- 20.45: *Coaches to hotels*

## Wednesday 24th October

### SCIENTIFIC SESSION 1. ANATOMY & PHYSIOLOGY

- 08.30: Invited lecture: Roy Weller
- 09.00: Invited lecture: Marek Czosnyka
- 09.20: Original papers
- 10.30: Morning break, The Temple Speech Room (exhibition hall)

### SCIENTIFIC SESSION 2. PATHOGENESIS

- 11.00: Invited lecture: Edward Oldfield
- 11.40: Original papers
- 13.00: Lunch will be served in The Temple Speech Room (exhibition hall)
- 13.30: Poster presentations in The Temple Speech Room

### SCIENTIFIC SESSION 3. INVESTIGATIONS

- 14.00: Invited lecture: Tatsuya Nagashima
- 14.30: Original papers
- 16.00: Afternoon break, The Temple Speech Room (exhibition hall)

### SCIENTIFIC SESSION 4. INVESTIGATIONS

- 16.30: Original papers
- 18.30: Supper & Entertainment. Temple Speech Room, Rugby School
- 20.45: *Coaches to hotels*

## Thursday 25th October

### SCIENTIFIC SESSION 5. CHIARI & HINDBRAIN RELATED SYRINGOMYELIA

- 08.30: Invited lecture: Thomas H Milhorat
- 09.20: Original papers
- 10.30: Morning break, The Temple Speech Room (exhibition hall)

### SCIENTIFIC SESSION 6. CHIARI & HINDBRAIN RELATED SYRINGOMYELIA

- 11.00: Original papers
- 12.10: Invited lecture: Dieter Grob
- 13.00: Lunch will be served in The Temple Speech Room (exhibition hall)
- 13.30: Poster presentations in The Temple Speech Room

### SCIENTIFIC SESSION 7. SPINAL DEFORMITY & PAEDIATRIC ASPECTS

- 14.00: Invited lecture: Jerry Oakes
- 14.20: Invited lecture: Harold Rekate
- 14.40: Original papers
- 16.00: Afternoon break, The Temple Speech Room (exhibition hall)

### SCIENTIFIC SESSION 8. POST-TRAUMATIC SYRINGOMYELIA

- 16.30: Invited lecture: Graham Flint
- 16.50: Original papers

- 18.15: *Coaches to hotels*
- 19.15: Coach to collect guests from hotels for Gala Dinner at the Paramount, Daventry
- 19.30: Champagne reception at The Paramount Daventry Hotel
- 20.00: Gala dinner
- 22.30: *Coaches to hotels*

## Friday 26th October

### SCIENTIFIC SESSION 9. OTHER FORMS OF SYRINGOMYELIA

- 08.30: Invited lecture: Jorg Klekamp
- 09.00: Original papers
- 10.30: Morning break, The Temple Speech Room (exhibition hall)

### SCIENTIFIC SESSION 10. VETERINARY ASPECTS & GENETICS

- 11.00: Invited lecture: Clare Rushbridge
- 11.20: Invited lecture: Dominic Marino
- 11.40: Invited lecture: Guy Rouleau
- 12.00: Original papers
- 13.00: Lunch will be served in The Temple Speech Room (exhibition hall)
- 13.30: Group Photograph, The Quad, Rugby School

### SCIENTIFIC SESSION 11. HISTORICAL ASPECTS & PATIENT PERSPECTIVES

- 14.00: The 2007 Holter prize winning essay: Helen Williams
- 14.20: Bernard Williams memorial lecture: Ulrich Batzdorf
- 15.00: Original papers
- 15.30: Invited lecture: Tony Kember

### SCIENTIFIC SESSION 12. CONCLUSIONS: BEST MANAGEMENT, FUTURE RESEARCH

- 15.40: Interactive question & answer session / Round table discussion
- 16.00: Afternoon tea, The Temple Speech Room (exhibition hall)

## Veterinary Syringomyelia 2007 Friday 26th October 17.00 - 21.00

For breeders, dog owners, veterinary surgeons & nurses

- 17.00: Canine syringomyelia  
Clare Rusbridge, Stone Lion Veterinary Centre
- 17.20: Human chiari malformation and syringomyelia  
Graham Flint, Queen Elizabeth Hospital, Birmingham
- 17.40: The search for the genes  
Guy Rouleau, University of Montreal
- 18.00: Breeding strategies to reduce inherited disease in pedigree dogs  
Sarah Blott, Animal Health Trust - Sponsored by Hills
- 18.20: Experiences in surgery for canine syringomyelia  
Dominic Marino, Long Island Veterinary Specialists - Sponsored by Novartis
- 19.00: Syringomyelia Question Time - Ask the Experts  
Chaired by Bruce Fogle
- 20.00: Supper served in The Temple Speech Room Exhibition Hall
- 21.30: *Coaches to hotels*



# Thank you everyone, it really was a great success

Syringomyelia 2007 was, by any measure, an outstanding success. Anyone who is anyone in the world of Chiari and syringomyelia was there. As a result, the event fed off itself. Each of the many international specialists present saw and acknowledged the presence of other experts in the field and could appreciate that their own journey to Rugby had indeed been worthwhile.

We are most grateful to all those delegates who attended, some 192 in total, coming from four continents. Some travelled from as far away as Australia, Japan, China and the west coast of America. We are particularly grateful to our international guest lecturers, who not only gave the conference status but who enlightened delegates with their presentations. There was also a great deal of original research material presented at Syringomyelia 2007, with some 70 oral and a further 20 poster presentations. The conference therefore reflected practice worldwide, in treating Chiari and syringomyelia, including the work of major specialist centres as well as that taking place in general neurosurgical units.

Those of us who have spent the last two years organising this event were well rewarded by what we saw and heard. Many of the delegates also went out of their way to express their thanks and all of our international celebrities indicated that Syringomyelia 2007 had been well conceived and a much needed event. There can be no doubt that everybody attending benefited significantly.

The Ann Conroy Trust and Syringomyelia-Chiari are now names that go together on the international stage. We next intend to make further and full use of modern, global electronic communication methods and set up a world-wide network of specialists who have an interest in

researching into and treating these conditions. We look forward to bringing you reports on this project in future newsletters.

For now we can all be well pleased with what we have achieved. A substantial amount of ACT money was invested in this project but all has been recovered from delegates' fees and sponsorship. Even without this income, the return on our investment, in terms of gathering, sharing and disseminating knowledge about Chiari and syringomyelia, has been substantial and invaluable.



I would therefore like to express my thanks to all of those who made Syringomyelia 2007 possible and such a great success. This includes all delegates, presenters and invited speakers, our UK faculty and our international advisors. I am also very grateful to the staff of Rugby school, in particular Sandra McPherson, Hugh Bennett, Chris Harris, Michael Ramsden and Jacquie Bradley, as well as the electricians, porters & catering staff. I must thank especially our own Karen Thacker & Becky Pitt as well as my other nursing colleagues Kat Phillips & Dymna McAleer. Spouses, partners and family members also joined in, including Jed Masters, Jonathon Thacker, Ted Watton and Bob Knight. My own wife, Marian, supported me throughout, allowing me to absent myself from domestic and family duties for long periods. Special thanks are due to Barbara Masters, who kept the whole event running. Most of all, we must thank Sue & Tony Kember, who saw the project through from start to finish and without whom Syringomyelia 2007 would not have taken place at all.

*Graham Flint*



*The McCready Theatre, Rugby School*



# Syringomyelia 2007, what did we learn?



**W**hen she set up her charity, over 25 years ago, Ann Conroy announced that she was going to "found an organisation to solve the problem of syringomyelia". In reality, syringomyelia takes on different forms and can be caused by a variety of underlying disease processes. It is unlikely, therefore, that there will ever be a single cure for the condition, in all its varieties. Solving the problem is more a case of gradually fitting together the pieces of a jigsaw puzzle.

Syringomyelia 2007 certainly did not, on its own, solve the various problems associated with this enigmatic condition. Nor did it complete the jigsaw. What it did was identify some more of the pieces and it has given significant impetus to the process of fitting them together.

The symposium extended over three days. It was divided into 12 sessions, each covering different aspects of syringomyelia and Chiari malformations. Topics were introduced by keynote addresses, each delivered by one of our 15 invited speakers, all of whom are international experts in their field. Sessions then continued with a selection of original papers, these presenting the results of various research projects taking place around the world. There were almost 70 such papers presented in total. In addition there were a dozen or more poster presentations on display.

The first day opened with a session covering relevant aspects of anatomy and physiology, with introductions from Professor Roy Weller from Southampton & Marek Czosnyka from Cambridge. Original papers looked at the mechanisms underlying the formation of Chiari malformations and the accumulation of fluid within syrinx cavities. The rest of the day concentrated on various methods of investigations used in the study of syringomyelia, including modern developments in MR scanning. Dr Nagashima, from Japan, introduced this session. On the Thursday we looked in more detail at hindbrain related syringomyelia and Chiari malformations, before moving on to paediatric aspects of these conditions. The day concluded with a session on post-traumatic syringomyelia. Friday covered other forms of syringomyelia, before we looked at veterinary aspects and genetics. This day also saw a review of the history of syringomyelia and how we have developed our current understanding of the condition, over the years. We were then addressed by two patient representatives, which ensured that everything that had gone before was placed in a proper perspective, i.e. what it is like to be a sufferer.

So what did we learn? To start in reverse and consider the veterinary and genetic sessions, it is clear that Chiari I hind brain hernias develop principally as a result of subtle abnormalities of bone formation at the back of the head and that this has a genetic basis. In some highly in-bred



varieties of dog, in particular Cavalier King Charles Spaniels, genetic traits such as this show through frequently and the majority of these animals develop syringomyelia. We were addressed on this subject by Clare Rusbridge from London and Dominic Marino from New York. In the human species most cases of Chiari I malformation occur randomly but occasionally the genetic basis will show in families with, for example, a parent and child having the condition. One of our other guest speakers, Guy Rouleau, is a geneticist working in Canada. He has a particular interest in the genetics of Chiari and has a large database of canine cases. He is currently trying to build, as well, a database of familial cases in humans.



Bony malformation at the back of the skull causes Chiari I to develop because it results in the posterior fossa of the skull being small. This is the part of the cranial cavity, at the back of the head, that contains the cerebellum. There were a number of presentations at the symposium covering work, in both dogs and humans, which looked at abnormalities of the volume and shape of the posterior fossa.

We recognise, of course, that many diseases in humans, as well as in other species, arise as an interaction between environmental factors and genetic predisposition. It was interesting, therefore, to learn of some work being carried out in Russia, regarding possible environmental influences on the development of Chiari malformations and syringomyelia. To date no such work has been carried out elsewhere but perhaps some other delegates at the conference have now been stimulated to consider such matters.

We know that there is a poor correlation between the degree of anatomical abnormality in the Chiari malformation and the severity of an individual's symptoms. Indeed, there is a condition described, referred to as Chiari 0, where a patient presents with typical symptoms but

without any apparent abnormality on a scan. Illustrative cases were presented at the symposium, including examples of positive responses to surgery.

Most of the presentations covering diagnostic investigations looked at the role of flow studies and other, newer MR techniques, which are better at detecting obstructions of CSF movement in the head and in the spinal canal. Another means of investigation is ultrasound imaging, carried out during surgery. There were also presentations and discussions regarding the role of electrophysiological investigations, before, during and after surgery.

Dr Thomas Milhorat, from the Chiari Center in New York, stressed, as part of his keynote address, that Chiari I malformations are a mixed group of conditions and he drew attention to a possible role of spinal cord tethering in some cases.

The symposium also benefited from useful contributions in the field of paediatrics, introduced by a lecture by Dr Jerry Oakes, from the USA. Dr Dieter Grob, from Switzerland, looked at spinal deformities in children and their possible relationship to syringomyelia.

Post-traumatic syringomyelia remains a very difficult condition to treat. Syringomyelia 2007 was attended by a number of delegates who specialise in the management of spinal cord injuries. Useful contributions to this topic were made by Dr Jorg Klekamp and Dr Alfred Aschoff, both from Germany. It is clear that we cannot hope to bring about spectacular improvements when operating for this condition but, for people who already have major physical disabilities, even minor improvements can be of significant value to them.



There were several audits of surgical results delivered at the

symposium. With these sorts of presentations individual surgeons have analysed the results of their surgical treatment for syringomyelia and/or hind brain hernia. The problem is that of then trying to pool all these results, so that we can generate useful conclusions and offer meaningful predictions to patients undergoing surgery. The main difficulty in doing this is that we have not, to date, developed a standard method of grouping patients. Syringomyelia, as we have already noted, is a mixed group of conditions. One audit might look at the results from one particular surgical procedure, carried out for different forms of syringomyelia. Another may look at the outcome for treating one form of syringomyelia but using a number of different operative techniques. These difficulties are compounded by the fact that we do not have a standard way of measuring the outcome following surgery. If there is one role that the Ann Conroy Trust can play in the future, as regards organising research internationally, it will be to develop standards in classification of syringomyelia and Chiari and for measurement of outcome following treatment for these conditions.

The principle scientific question regarding syringomyelia, one that has exercised generations of neurosurgeons over the years, is that of just why does CSF accumulate within the substance of the spinal cord when the normal channels for CSF flow become obstructed. Dr Ulrich Batzdorf, from Los Angeles, summarised the many theories that have developed over the years, during his historical review of the subject. He acknowledged the contributions made by James Gardner and Bernard Williams. In more recent times significant contributions have been made by Dr Edward Oldfield & Dr Harold Rekeate, from the USA and Dr Marcus Stoodley, from Australia. We were privileged to have these three experts with us at Syringomyelia 2007, presenting some of the work upon which their theories have been developed.

One of the approaches to answering this question is that of mathematical modelling. The problem here is bridging the

gap in knowledge between mathematicians and neurosurgeons, given in their very different fields of expertise. Each has to take a fair amount on trust from the other but we are fortunate to have two or three groups around the world working in this area and we can look forward to further output from them in the future.

Unfortunately, despite the considerable efforts and contributions made by all these experts we are left, at the end of Syringomyelia 2007, still perplexed by this curious phenomenon and it is clear that more research needs to be carried if we are to understand, ultimately, just why CSF accumulates inside the spinal cord. When we do, it will not necessarily allow us to deal with all the problems related to syringomyelia but it should help us place our treatment methods on a more rational basis.

This conference summary may not be reporting spectacular discoveries in the field of syringomyelia and Chiari but we are not in the business of producing dramatic headlines about medical breakthroughs. We have, instead, to work in a steady, sober way. We must also work in a spirit of cooperation, if we are to achieve Ann Conroy's aims. Perhaps the greatest achievement of Syringomyelia 2007 was that it went a very long way towards fostering this process. All those delegates who came up and spoke to the organisers were effusive in their praise. All of our international speakers were delighted to have had the opportunity to address the symposium and were pleased to meet the many other experts in this field, from around the world. At the end of the conference there was a general view that we "must keep this group together". We intend to do so. The Ann Conroy Trust will now move forward on the international stage, with the support of our members and that of affiliated groups overseas. We hope to promote international research programmes, with the aim of furthering our understanding about syringomyelia and related disorders, for the ultimate benefit of all those who become victims of these conditions.

*Graham Flint*



## A trustee's perspective...

Syringomyelia 2007 was the first (and hopefully not the last) International Symposium I have ever been actively involved with in my nursing career. Even though most of the trustees went through many states of emotion before and during the week long symposium, we all arrived at Rugby School on Monday 22nd October 2007 with a lot of nervous excitement to prepare the venue, still wondering if any of the delegates would appear. We need not have worried as the first delegate actually came that morning, but unfortunately was twenty four hours too early. However, Dr Yong Lui was made extremely welcome by us all as he had just arrived from The Peoples Republic of China!



For me, the success of Syringomyelia 2007 came from the benefits of two extremely important factors. Firstly, there was the great bond in the team of trustees and helpers of the charity who organised the international symposium. I believe the main success of the event was the vision, careful planning and the great effort given by Tony, Graham and Barbara to make the symposium an outstanding success. The inspired surroundings and the wonderful facilities of Rugby School, helped motivate and bond the team of organisers and helpers. We all became great friends over the week, and it showed that even though at times it was hard work we all enjoyed the time greatly. Special thanks must also be given to the support staff at Rugby School, who helped us during the week in preparing and maintaining the venue, they were extremely professional, as well as providing IT and catering support.

Secondly, as a Syringomyelia Specialist Nurse, the main outstanding success of the symposium was to bring together the many international medical experts into one place, with the purpose of improving and increasing the awareness of Syringomyelia, hindbrain hernia and related

disorders. Meeting, listening and speaking to these experts has improved my knowledge of these conditions. Not only the flow of information between these experts in the lectures and papers impressed me, but how the informal conversations and networking of these experts during breaks from lectures showed how focused all these delegates were during the week. Again, this will greatly improve the knowledge and understanding of these disorders to ultimately help sufferers and their carers. Many of the experts stated that they were overwhelmed at the number of leading international neurosurgeons present at the symposium, a feat which had never been achieved previously.

The greatest reward at the end of the symposium was that it raised the profile of the Ann Conroy Trust as well as hopefully long term helping sufferers and their carers all around the world to gain a better knowledge of Syringomyelia, hindbrain hernia and related disorders.

*Karen Thacker  
Trustee & Syringomyelia specialist nurse*

## Ann Conroy Trust Chairman's Report

A lot of work by a lot of dedicated people made this international syringomyelia conference an outstanding success and Ann Conroy Trust members must be acknowledged for their generous support..

After 2 years planning Syringomyelia 2007, the event was our main objective, but so much has come from it and we are now drawing up our agenda for several new projects.

We will be co-ordinating an international support group of syringomyelia professional carers drawing from Syringomyelia 2007 delegates. Already leading syringomyelia specialists from around the world have signed up for this idea.

We are also forming an alliance with European syringomyelia patient groups whose main task will be to lobby the EU for funding for more research. Karim Berkouk, the Minister for EU Medical Funding attended the symposium and has indicated to me that funds may be available. So far groups to express interest in joining include France, Luxembourg, Holland, Spain, Germany and Italy.

Dr Lui Yong, Neurosurgeon at the Syringomyelia Department of The General Hospital of Beijing, China, has

expressed a great interest in working with us, he and his colleagues have developed Chinese Medicine for the specialist treatment of syringomyelia. We intend to develop this relationship.



The more organisations we work with in our quest to improve the treatment, care, and general well being of syringomyelia sufferers the sooner we can help those living with the condition.

We will also be producing a monograph based on the specialist lectures given at Syringomyelia 2007 which will be edited by Graham Flint and his colleagues. This will be published by a specialist medical publishing house for distribution worldwide to the medical profession.

The British Journal of Neurosurgery, the official journal of The Society of British Neurological Surgeons published in it's October edition the entire proceedings, abstracts and keynote presentations of Syringomyelia 2007.

There is still much to do but I now feel that The Ann Conroy Trust is moving forward in our efforts to improve the quality of life of sufferers of syringomyelia/Chiari.

*Tony Kember*



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