2012 National Spina Bifida Conference
“Australian Masterclass”

Novotel Sydney Olympic Park | Sydney, NSW

19th and 20th October 2012

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Information Booklet

www.nswspinabifidacollab.org.au
Welcome from the NSW Spina Bifida Collaborative Group

Dear Colleagues,

It is our pleasure to welcome you to our National Spina Bifida Conference, at the Novotel, Sydney Olympic Park in Sydney, New South Wales.

The NSW Spina Bifida Collaborative Group held its inaugural meeting at The Children’s Hospital Westmead on 10th November 1999. The Spina Bifida Collaborative Group was first initiated as a means of networking and sharing information between the two major children’s hospitals in NSW caring for young people with Spina Bifida. In 2000 the Collaborative Group included Adult Spina Bifida Health Services and Northcott Disability Services. In 2003, the Spina Bifida service from John Hunter Children’s Hospital joined the group. Since the inaugural collaboration meeting the collaborative group has held twice yearly meetings and currently has over 30 committee members from a diverse mix of government and non-government organisations.

This conference has attendees from all over Australia, New Zealand, Sweden and USA and is a truly multi-disciplinary event. Please take the opportunity to network with as many people as possible. We are thrilled you could join us to make this a memorable event that will benefit the lives of people living with Spina Bifida.

Abstracts and presentations will be available on our website after the conference.

Julie Dicker
Secretary
The NSW Spina Bifida Collaborative Group and Conference Organising Committee

Organising Committee
Julie Dicker
Joanne Brady
Charles Scarf
Antoinette Botman
Jason Birse
Julianne Lane
Gai Lovell

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Brad Dicianno, MD is an Assistant Professor in the Department of Physical Medicine and Rehabilitation at the University of Pittsburgh Medical Center, Pennsylvania USA. He is the Director of the Adult Spina Bifida Clinic, the Director of the UPMC Center for Wellness for Individuals with Spina Bifida and Spinal Cord Injury, and the Medical Director of the Center for Assistive Technology. He is also the Associate Medical Director of the Human Engineering Research Laboratories. His research interests focus on developing and studying interventions targeted to improving health and wellness in individuals with complex disabilities including Spina Bifida (wheelchairs, adaptive sports, telemedicine, virtual reality, and preventative care programs). He completed an NIH fellowship within the Rehabilitation Medicine Scientist Training Program. Brad also holds a Master’s Degree in Bioengineering.
Key Note Speaker

Dr Carolyn West AM

Carolyn West graduated from the University of Sydney with honours in 1969 and has postgraduate studies in Paediatric Child Development and Disability. She was the Head of the Spina Bifida Unit at The Children’s Hospital Camperdown then Westmead from 1979-2011. She also has been a Visiting Medical Officer at the Royal Prince Alfred Hospital from 1982 to present (Carolyn was the first doctor to set up an adult spina bifida service in NSW). She is a Professional Member of the Guardianship Tribunal of NSW 1989 to present. Carolyn received a Member of the Order of Australia [AM] in 2007. Her main area of interest is provision of the best possible medical care for children and adults with Spina Bifida within the context of the holistic needs of the individual patient and their circumstances. She also has a keen interest in advocating for people with disabilities to have the opportunities to enjoy healthy, happy and productive lives within the community.
We have been supported by many trade representatives. Please take the opportunity to visit their trade displays and thank them for their sponsorship of this conference. The following companies have agreed to attend:

COLOPLAST
BRIGHTSKY AUSTRALIA
INDEPENDENCE AUSTRALIA
WELLSPECT HEALTHCARE
INDEPENDENT LIVING SPECIALISTS
NICE PAK PRODUCTS
NORTHCOTT DISABILITY SERVICES
NIGHT ‘N’ DAY COMFORT
KEY MEDICAL

*We also thank the ROYAL AUSTRALIAN NAVY BAND; SHINE AUSTRALIA; AKUBRA HATS; JOSOPHAN’S FINE CHOCOLATES and NOVOTEL SYDNEY OLYMPIC PARK for their Sponsorship and to our photographer Jodie Thompson (Chocolate Photography and Design).

*SPECIAL THANKS TO THE SYDNEY CHILDREN’S HOSPITAL NETWORK EXECUTIVE AND KIDS REHAB DEPARTMENT AT THE CHILDREN’S HOSPITAL AT WESTMEAD FOR THEIR FINANCIAL AND PRACTICAL SUPPORT THAT MADE THIS CONFERENCE COME TO FRUITION.
Preliminary Program - Friday 19th October, 2012
(Subject to change)

Opening
Welcome Dr Charles Scarf (Committee member)
Opening address John Della Bosca
Antenatal Consultation Dr Antoinette Botman - NSW
Denying Disability: the increase in disability directed terminations, a parent's perspective Diane Belcher - NZ
The complexities of nursing an infant with a Lumbosacral Myelomeningocele Caroline Karskens - NSW
Perinatal Management Ethics Discussion panel

Morning Tea
Key Note Address - Technology for Self- Management Dr Brad Dicianno - USA
Understanding Non Verbal Learning Disorder Dr Carol Russell and Tally Russell - USA
To get things done - Challenges in everyday life Dr Marie Peny-Dahlstrand - Sweden
Australian study into learning experiences of students with shunted hydrocephalus Dr Barbara Rissman - QLD

Lunch
Urology Update Dr Danielle Delaney - NSW
Orthopaedic Update Dr Paulo Selber - VIC
Spinaweb: Impact of a true multidisciplinary approach Kaleidoscope Rehabilitation Service
What we do when there are no cyclones or floods Bill Shead - QLD

Afternoon tea
Holistic assessment of pressure ulcers Dr Bonne Lee - NSW
Plastic surgery and Spina Bifida Dr Sandrine Roman - NSW
Pressure management model of care Louise Kelly - NSW
Foot assessment for the patient with Spina Bifida Luke Taylor - NSW
Meeting of State Spina Bifida Associations
Pre-Dinner Drinks and Conference Dinner
Preliminary Program - Saturday 20th October, 2012

(Subject to change)

Key Note Address - Hospitalisations and Preventable Conditions in Adult Spina Bifida
Dr Brad Dicianno - USA

Spina Bifida Adult Resource Team
Unlocking potential, the goals approach
Jade Baynes and Lynne Brodie - NSW
Sonya Dennis and Jodie Kennedy - QLD

Fertility Issues in Adults Spina Bifida
Dr Carolyn West – NSW

Morning tea
Can we improve physiotherapists knowledge about managing children with Spina Bifida through online learning?
Nicole Thomas - QLD

Neuropsychology in Spina Bifida
Dr Ellen Northcott - NSW

Shunt register update
Dr Andrew Chow - NSW

Neurosurgery panel discussion
Dr Ray Chaseling, Dr Warwick Stening, Dr Andrew Chow – NSW

Lunch
Workshops and discussion groups:

- Physiotherapy Workshop
- Occupational Therapy – “Mobility across the lifespan”
- Continence Management - Bladder & Bowel
- Understanding Executive Functioning Issues in People living with Spina Bifida

(Each workshop will go for one hour and be repeated giving you the opportunity to attend two different sessions)

Afternoon tea
Monash Children’s Spina Bifida Database Project
Dr Sabine Hennel - VIC

Key Note Address - Spina Bifida Model of Care
Dr Carolyn West - NSW

Closing remarks and presentation of awards (best paper, best poster presentation)
Dr Charles Scarf
SPEAKER PROFILES: (FRIDAY)

- **John Della Bosca:** served in the New South Wales Parliament for 12 years, during which time he served as Assistant Treasurer, Special Minister of State, Minister for Health, Minister for Education and Training, Minister for Workcover and Industrial Relations, as well as Minister for Disability, Ageing and Home Care. He was instrumental in the development and introduction of the New South Wales Lifetime Care Authority, which provides treatment, rehabilitation and care to individuals injured in motor vehicle accidents. John was also responsible for the development and implementation of Stronger Together, a program of reforms designed to better meet the needs of people with a disability, their families and carers in New South Wales. **John has been Campaign Director for the National Disability Insurance Scheme since August 2010.**

- **Dr Antoinette Botman:** a Paediatric Rehabilitation Consultant at The Sydney Children’s Hospital Network (SCHN), located at the Westmead Campus (CHW). She completed her training in Rehabilitation Medicine in The Netherlands in 2006. She continued her post-graduate training in Paediatric Rehabilitation Medicine at CHW. She obtained fellowship with the Australian Faculty of Rehabilitation Medicine in 2009. She works as a Staff Specialist in the Kids Rehab Department in the Cerebral Palsy and Movement Disorders Service; Brain Injury Service; Spinal Cord Injury and Disease Service. She has been the Head and Medical Co-ordinator of the Spina Bifida Service since 2011 and has also just been appointed the Head of the Spinal Cord Injury and Disease Service. She has been a member of the NSW Spina Bifida Collaborative Group since 2007. Her passion is working with families and children with congenital and acquired complex disabilities, in particular children with Neural Tube Defects and Spina Bifida, to help them achieve the child’s full potential.

- **Diane Belcher:** In 2009 Diane’s son Daniel was born at Waikato Hospital NZ with Spina Bifida after being diagnosed in-utero at 20 weeks. After his birth, as a trained Support Parent, Diane began to hear of the experiences shared by other parents of children with Spina Bifida. In 2010 she began a campaign to improve the information and environment surrounding foetal abnormality diagnosis. In July 2011 Diane formed Spina Bifida New Zealand which now has over 120 members. Diane has been invited to speak at several conferences in New Zealand and has been an active advocate for the Spina Bifida community providing information and support. She has written submissions on Prenatal Surgery, Antenatal Screening and Folate Fortification and is passionate about disability discrimination.

- **Caroline Karskens:** Caroline is a Registered Nurse who has worked in the Grace Centre for Newborn Care for over 25 years, as a clinical nurse and currently as the Clinical Audit Nurse. Her interests include the care of complex surgical neonates and how we as clinicians are instrumental in improving outcomes for babies and their families. She is also interested in data collection and research to measure outcomes of newborn intensive care.
• **Dr Carol Russell:** is a **Professor of Early Childhood** at **Emporia State University, KANSAS USA,** has a doctorate in Special Education; and a master’s degree in Human Development and Family Studies; and a B.A. in Art, minoring in Psychology. She has been in the field of Early Childhood & Special Education for over 35 years, and teaching higher education for 30 years. She and her husband, Fletch, are creators and co-executive producers of **I Can Move,** an inclusive creative movement video series for children with differing abilities, produced with Public Television. She has been a facilitator for SIBSHOPS (supportive workshops for siblings of children with special needs). Carol has been a speaker at many conferences and authored several books. The Russells have three lovely daughters: Cassie, Mikelle and Tally. Tally was born with Spina Bifida, along with several other medical complications. Their lives have been enriched beyond comprehension, and they have learned so much from her. They have experienced the education system as parents, both from the gifted education and the special education arenas. Balancing the “parental hat”, as well as the professionals can be interesting, to say the least!

• **Tally Russell:** is a **recent graduate of Emporia State University, KANSAS USA with a Bachelor of Integrated Studies, and a concentration of Sign Language and Early Childhood.** She is studying to be a Sign Language Interpreter for young children. Tally has been enthusiastic about rocks her entire life. Tally recently co-authored a children’s book, **I Like Rocks.** Over 20 years of Tally’s life enjoying rocks, are captured in the photos and story. Tally is currently working on two more books: a children’s book about therapeutic horseback riding; and a book reflecting on her life story. Tally has co-presented at local, state and national conferences on a variety of topics, including: Inclusive Creative Movement, Nonverbal Learning Disorder, ADA and accessibility, Person First Philosophy, and advocacy.

• **Dr Marie Peny-Dahlstrand: PhD, reg. Occupational Therapist.** Marie is working as a senior Occupational Therapist in habilitation at the Regional Rehabilitation Centre (Regionhabiliteringen) at Queen Silvia Children’s Hospital in **Gothenburg, Sweden.** She has been working clinically as an OT in children rehabilitation for over three decades. The reason that she went into research about children with Spina Bifida was that she was puzzled and challenged about why the cognitive/executive difficulties, often seen in this group, were never considered as a hindering factor for independence and low rate of participation, and that the children thereby were not given appropriate support. Her dissertation was defended in 2011 at the University of Gothenburg, were she also lectures at the Occupational Therapy program.

• **Dr Barbara Rissman:** Doctoral studies were inspired by her daughter who was born with a lesion at the back of the head called an **Encephalocele.** Her research explored the learning experiences of students with shunted hydrocephalus, Spina Bifida and Nonverbal Learning Disability (NLD). Her interests include raising awareness of the NLD profile, post-school prospects for individuals with NLD, and equity and funding issues. She has published in the British Journal of Learning Disabilities and is presently writing a book about NLD for the Australian Council of Education Research. In Queensland University of Technology’s Education Faculty she works as an Equity Project Officer and has been involved with tutoring, research and evaluation projects in disability and widening participation.
- **Dr Danielle Delaney: Paediatric and Adult Urologist FRACS (Urol).** Danielle is accredited in all aspects of urology and has completed a Fellowship in Paediatric Urology. She is currently appointed to the Sydney Children’s Hospital Network (SCHN) Randwick campus and also has a private practice on the Lower North Shore of Sydney. In adults, she has a special interest in endoscopic urology including bladder cancer, urinary tract infections and stones. In children, she has a special interest in congenital kidney and bladder pathology and voiding issues. Danielle presented on Urodynamics in children and Surgical Options for Neurogenic Bladder Dysfunction at the Kids Bladder Day at The Children’s Hospital at Westmead in March 2012.

- **Dr Paulo Selber: an Orthopaedic Surgeon in Neuromuscular Diseases.** Medical Degree in Brazil. Fellowships in Neuromuscular Disease: 1st Association for Assistance of the Disabled Child Sao Paulo (AACD); 2nd Northwestern University Chicago Children’s Memorial Hospital; 3rd University of Minnesota Gillette Children's Hospital - Consultant Orthopaedic Surgeon AACD and Clinical Director of AACD Movement Analysis Lab until 2001; Senior Staff Specialist - Children's Hospital Westmead 2003-2012; Senior Staff Specialist - Royal Children's Hospital, Melbourne 2001-present; **Membership:** Brazilian Society of Orthopaedics and Trauma; Brazilian Society of Paediatric Orthopaedics; American Academy of Cerebral Palsy and Developmental Medicine.

- **Kaleidoscope Paediatric Rehabilitation Service (Newcastle area of NSW):** The Spina Bifida Service within the Kaleidoscope Paediatric Rehabilitation Service (KPRS) is a multi-disciplinary team that has been working together for a number of years. Our service provides care for clients within the northern child health network. The members of our team include Dr Caroline Hodge (Paediatric Rehabilitation Specialist), Dr Chanka Nanayakkara (Fellow in Paediatric Rehabilitation), Odette Treyvaud (Physiotherapist), Sharon Bird (Clinical Nurse Consultant), Jeni White (Social Worker) and Gai Lovell (Occupational Therapist). Each member of our team has a commitment to best possible service delivery for clients with Spina Bifida and other neural tube defects and their families. Many of the team members have been working with this client group for a number of years, (some with over 20 years of experience in this clinical area). We work together with clients, families, department of education, medical specialists and other service providers to ensure access to quality health care and support.

- **Bill Shead: Bill has worked for SBH Queensland for 19 years.** Initially his work involved counselling with adults but following a small organisational restructure he undertook the role of Information Officer, a role he continues to fulfil. When the previous manager resigned in 2006, Bill took on the position of manager as well. He continues to hold both positions with SBH Queensland.
- Dr Bonne Lee: Research Fellow, (Neuroscience Research Australia); Senior Staff Specialist, Spinal Unit Prince of Wales Hospital – Randwick NSW; Conjoint Senior Lecturer, Faculty of Public Health, UNSW; Visiting Fellow, Centre for Clinical Governance Research in Health, UNSW. Dr Bon San Bonne Lee is a spinal cord injuries (SCI) specialist physician and researcher who has developed a broad, collaborative research perspective in the area of SCI and is a leader in the area of SCI urinary tract infection (UTI) prevention. His training is uniquely multidisciplinary, having postgraduate Masters degrees in clinical epidemiology (USYD), management (health administration UNSW) and a graduate certificate in information technology (UTS) as well as his specialist AFRM/RACP qualifications including the rehabilitation college medal for his fellowship exams and the Adrian Paul prize for research for new fellows.

- Dr Sandrine Roman: MBBS (Honours), BSc(Med)(Honours), FRACS, PhD
  Sandrine is a Plastic and Reconstructive Surgeon at The Children's Hospital at Westmead, the Royal North Shore Hospital and the Northern Beaches. Her main interests are in cleft lip and palate surgery, paediatric plastic surgery and adult aesthetic surgery. Her secondary interests include research into wound healing. She has received several scholarships and awards for research including the Sir Roy McCaughey Surgical Research Fellowship and The Surgeon Scientist Research Scholarship. She completed a PhD in The Role of Gene Therapy in Plastic Surgery. She has several publications/presentations at national and international meetings.

- Louise Kelly: BN, MN (Professional Studies), Grad Cert Health SCI (Sexual Health).
  Louise has 20 years of experience in nursing at all levels of the profession with the last 12 spent in the speciality of spinal cord injury. In addition to a Bachelor in Nursing degree, she holds a Double Master’s degree in Education and Management as well as a Graduate Certificate in Sexual Health. Her current position is the Clinical Nurse Consultant (CNC) at the Royal North Shore Hospital and she previously held the position of CNC for the Spinal Plastics Service at the same facility. For the past 12 months she has been seconded to The Agency for Clinical Innovation to develop a Statewide model of care for pressure injury prevention and management in individuals living with Spinal Cord injury and Spina Bifida.

- Luke Taylor: is the Acting Director of Podiatry for Sydney South West Local Health District. Luke has over 10 years of experience caring for patients with foot ulceration, particularly in the field of diabetes and has completed post graduate studies in diabetes education and management. He has held teaching roles at the University of Western Sydney, and currently sits on the UWS podiatry course advisory panel. Along with colleagues Dimitra Psihramis and Dr Cameron Ly has an interest in management of lower limb ulceration in people with Spina Bifida.
SPEAKER PROFILES: (SATURDAY)

- **Jade Baynes & Lynne Brodie:** Jade is a registered Occupational Therapist. She has worked in a variety of clinical areas including acute, rehabilitation and community care. Jade moved to her current role as senior occupational therapist with the Spina Bifida Adult Resource Team (SBART) in 2010. SBART aims to provide clinical consultation, education, support and preventative health strategies to adults living with Spina Bifida. Lynne is a registered nurse with over 40 years of experience in the health system. The majority of her nursing career was spent at the Royal Alexandra Hospital for Children in Sydney and The Children’s Hospital at Westmead where she held a variety of positions including Nurse Educator, Nursing Unit Manager and Manager of Clinical Operations. Lynne moved to her current role as NSW Transition Care Network Manager in 2004 and leads a state-wide team whose aim is to improve the systems and processes for young people with chronic complex illnesses transitioning from paediatric to adult health services.

- **Sonya Dennis & Jodie Kennedy:** Sonya and Jodie are social workers with SBH Queensland, Australia. They have a combined total of 27 years of experience working with and counselling adults with Spina Bifida and Hydrocephalus. Sonya and Jodie specialise in the personal and emotional health and well-being of the people they work with. Sonya has a background in community development and disability. She is passionate about advocacy and the rights of people with disability. Other interest areas include counselling and working from a strengths based perspective. Sonya also has Spina Bifida. Jodie has also come from a background of community work. Jodie’s areas of interest include social justice and group work. Together they have developed and implemented ASSIST (Adult Services Skills, Information and Support Service), the only funded Spina Bifida specific, Adult Community Service in Queensland. Within the ASSIST service is the GOALS program. GOALS is an innovative approach that has seen improved results in tackling age old issues such as lack of motivation, compliance, anxiety and depression, family dynamics and interpersonal relationships.

- **Nicole Thomas:** Nicole is an Advanced Physiotherapist at the Royal Children's Hospital in Brisbane and has worked with children with Spina Bifida for the past 13 years. In 2011 she developed an eLearning package for physiotherapists to enhance the management of children with spinal disabilities within their local communities.

- **Dr Ellen Northcott:** Ellen is a Clinical Neuropsychologist working in the Kids Rehab and Neurology departments at the Children’s Hospital at Westmead. She completed her Doctorate in Clinical Neuropsychology in 2007, before beginning work at CHW. In her position at Kids Rehab she primarily works with children with Spina Bifida, brain injuries and movement disorders, such as Cerebral Palsy.

- **Dr Andrew Chow:** Andrew graduated from The University of Queensland in 2005. He has worked in various neurosurgery units including Royal Melbourne, Royal North Shore and Westmead Hospitals. Andrew currently works as a paediatric neurosurgery registrar at The Children’s Hospital at Westmead.
Dr Ray Chaseling: MBBS, FRACS, Grad Dip Med. Staff Specialist Neurosurgeon (The Children’s Hospital at Westmead - CHW). Ray graduated from Sydney University in 1974 and undertook neurosurgical training at RPAH and RAHC 1978 – 1981. Ray was a Senior Registrar in Neurosurgery at Royal Infirmary, Western General and Children’s Hospital, Edinburgh UK 1981 -1984. Appointed to Westmead and RAHC as visiting neurosurgeon 1984. Head of Department of Neurosurgery Westmead Adult Hospital 1990 – 1996. Head of Department of Neurosurgery at CHW since 2002 – present. Ray is also a Clinical Risk Manager with the Clinical Governance Unit at CHW. Special Interest areas are all aspects of paediatric neurosurgery with a particular interest in spinal dysraphism and hydrocephalus with many years of experience in endoscopic procedures. Ray also has expertise in selective dorsal rhizotomy for spasticity and craniofacial surgery.

Dr Warwick Stening: Warwick graduated in Medicine at Sydney University in 1968. He commenced training in neurosurgery in Edinburgh in 1972 and developed his interest there in paediatric neurosurgery. During his time in Edinburgh, the surgical management of myelomeningocele transitioned from paediatric general surgeons to neurosurgeons. This resulted in an immediate improvement in the neurological function of Spina Bifida babies. Hand in hand with this, neurosurgeons instituted the aggressive management of hydrocephalus to preserve brain function. He continued this training on his return to Australia, working in the Prince of Wales Children’s Hospital (later named Sydney Children’s Hospital, Randwick), and continues his interest in Spina Bifida. On attaining consultant status in 1978, he became an integral member of the multidisciplinary Spina Bifida Clinic at SCH - Randwick. Shortly after he joined the staff, he and Dr Robert Jones developed the technique, and published the seminal paper reporting a sizeable series of endoscopic third ventriculostomy, the first effective treatment for hydrocephalus that avoided shunts. This procedure has now become a standard operation throughout the world. Through his membership of the International Society for Paediatric Neurosurgery (ISPN) he has exchanged ideas and participated in the cross fertilisation that has been essential to the continuing improvement in the treatment of this devastating disease. The ISPN recently held its annual scientific meeting in Sydney, a great honour for Sydney’s neurosurgical fraternity. Most importantly, he has conveyed his years of experience in the management of Spina Bifida to a large number of neurosurgical trainees, giving them the foundation to continue caring for children and adults in this discipline, and to further refine treatment techniques.

Dr Sabine Hennel: is a Paediatrician at Monash Children’s in Melbourne VICTORIA where she works in the Developmental Medicine Unit and in the Victorian Paediatric Rehabilitation Service. She is clinical director of the Monash Children's multidisciplinary Spina Bifida clinic, which she has been directing for 6 years. Her interests include holistic care of children with complex disabilities.

BEST PAPER AND POSTER PRESENTATION AWARDS ARE GIVEN IN MEMORY OF MISS SIMONE HILE (who died on 9th September 2012 – after living with Spina Bifida for 42 years.)
WORKSHOPS (SATURDAY AFTERNOON)
Each workshop will go for one hour and be repeated giving you the opportunity to attend two different sessions.

- CONTINENCE WORKSHOP – Bladder & Bowel (Freshwater 2)
  Facilitators: Julie Dicker (Spina Bifida Clinical Nurse Consultant at The Children’s Hospital at Westmead for the past 19 years) Jason Birse (Neuro Rehab Clinical Nurse Consultant at The Sydney Children’s Hospital at Randwick for the past 5 years).

- UNDERSTANDING EXECUTIVE FUNCTIONING ISSUES IN PEOPLE LIVING WITH SPINA BIFIDA – (Freshwater 3)
  Facilitator: Dr Carolyn West.

- PHYSIOTHERAPY WORKSHOP – (Marine 1)
  Facilitator: Suzie Taylor (Senior Physiotherapist at The Children’s Hospital at Westmead Spina Bifida Service for the past 20 years).

- OCCUPATIONAL THERAPY WORKSHOP – (Marine 2) “Mobility across the lifespan”
  Facilitators: Jade Baynes (SBART) Rebecca Hudson (SBART) Gai Lovell (Spina Bifida Service, KPRS) Claire McDonagh (Spina Bifida Clinic, Sydney Children’s Hospital) Catherine O’Sullivan (Spina Bifida Clinic, The Children’s Hospital at Westmead)

A special interest group was developed out of the NSW Spina Bifida Collaborative Group to discuss specific issues regarding wheelchair prescription for clients with Spina Bifida. Members utilised this group to problem solve similar challenges, and share available evidence and experience to ensure best practice in relation to wheelchair and seating prescription for this client group. As part of this process Occupational Therapists from within this group have joined together to present on mobility across the lifespan: issues and considerations to optimise function.

The facilitators of this workshop are all OT’s working with individuals with spina bifida and neural tube defects. Their workshop combines a review of the evidence and literature in this field with clinical expertise and experience, to present key aspects which should be considered when prescribing a wheelchair for an individual with Spina Bifida.
• A survey of Adult Spina Bifida Clients attending a Multi-disciplinary Clinic: a trainee’s perspective – Dr N Gupta

• Functional Outcomes after intravesical botox in management of neurogenic bladder in Spina Bifida – J. Ganeshkumar, V. Raykar

• Growing up with Spina Bifida: Resources for families – Susan Sims, Deborah Daley, Julianne Lane


• Fun times in H2O….hydrotherapy for children with Spina Bifida and Hydrocephalus – Trish Sim, Elizabeth Steele and Therese Dwyer

• The Yellow Brick Road – a Target Approach – Emily Moore and Lynette Chakerian

• Working towards confident mobility: Wheelchair Skills for Kids – Trish Sim and Elizabeth Steele

• The Importance of Group Activities in addressing the Social, Physical and Emotional Wellbeing of people with Spina Bifida – Elizabeth Logan (Spina Bifida Foundation Victoria)

• Emotional Wellbeing – as important as Physical Wellbeing – Joan Abbott

• Improving Quality of Life in Patients with Spina Bifida – Surgical Options – Carolyn West and Julie Dicker
IMPORTANT INFORMATION!

• PLEASE TURN ALL MOBILE PHONES AND TABLET DEVICES TO SILENT

• PLEASE WEAR YOUR NAME TAGS AT ALL TIMES AS THIS ENABLES STAFF TO KNOW THAT YOU ARE A PARTICIPANT AND ELIGIBLE FOR ALL MEALS (lunch will be served downstairs in the Boulevard Brasserie)

• ORGANISING COMMITTEE MEMBERS HAVE BLUE BADGES SO THEY CAN BE IDENTIFIED IF YOU HAVE QUERIES ABOUT THE CONFERENCE

• A RED OR BLUE COLOURED DOT ON YOUR NAME TAG IS YOUR ENTRANCE TO THE CONFERENCE DINNER ON FRIDAY NIGHT

• A SILVER COLOURED DOT ON YOUR NAME TAG IS FOR PRESENTERS

• A YELLOW COLOURED DOT IS FOR THOSE ATTENDING FRIDAY ONLY

• A GREEN COLOURED DOT IS FOR THOSE ATTENDING SATURDAY ONLY

• FREE 30 min/day WIRELESS INTERNET available (ask for password at Registration Desk)

• PHOTOGRAPHS WILL BE TAKEN DURING THE CONFERENCE

• A LIST OF DELEGATES WILL BE AVAILABLE AFTER THE CONFERENCE ON REQUEST

• CERTIFICATES OF ATTENDANCE WILL BE AVAILABLE AT THE REGISTRATION DESK ON SATURDAY AFTERNOON