

Specialist, Paediatric Rehabilitation Medicine.

2011- Narrabeen Sports Medicine Centre, Sydney Academy of Sport, Wakehurst Parkway, Narrabeen NSW 2101 Australia

Delmar Private Hospital, 50 Quirk Street, Dee Why NSW 2099 Australia

My private practice includes children and young adults (up to 25 years old) with complex pain, disabling fatigue, musculoskeletal conditions, difficulties with motor skills and Joint Hypermobility/Ehlers-Danlos. Intensive day rehabilitation programmes are provided at Delmar.

2010- The Children's Hospital at Westmead, cnr Hawkesbury and Hainsworth street, Westmead NSW 2145 Australia.

I provide interdisciplinary care to children and adolescents with congenital and acquired limb loss and disabling musculoskeletal conditions (skeletal dysplasias, joint hypermobility/Ehlers-Danlos syndromes, Arthrogryposis, Osteogenesis Imperfecta and related connective tissue dysplasias). The functional impairments we commonly encounter include joint contracture, joint instability, early degenerative joint disease and pain and fatigue. I also provide care for children with neurological disability.

Qualifications:

FRACP	Fellowship of the Royal Australian College of Physicians (RACP) (Paediatrics) 2009
FAFRM	Fellowship of the Australasian Faculty of Rehabilitation Medicine (AFRM), RACP 2008
MSPMed	Masters in Sports Medicine, University of New South Wales, Australia 2006
MRCPCH	Membership of the Royal College of Paediatrics and Child Health (RCPCH), UK, 2001
DCH	Diploma in Child Health, RCPCH 2000, UK
MBBS	Bachelor of Medicine, Bachelor of Surgery St Bartholomew's and the Royal London Hospitals, University of London, UK 1998
BSc	Bachelor of Science with First Class Honours, University of London, UK 1995

Professional Accreditations and Organisations

Chair, Paediatric working group of the Ehlers-Danlos Society International

Medical Advisor, Short Statured People of Australia

Fellow, Australasian Faculty of Rehabilitation Medicine

Fellow, Royal Australasian College of Physicians

Member, Royal College of Paediatrics and Child Health (UK)

Member, International Society of Prosthetics and Orthotics (ISPO)

Member, Sports Medicine Australia

Member, hEDS/HSD classification committee of the Ehlers-Danlos Society International

AHPRA: Full National General and Specialist (Paediatrics, Rehabilitation) Medical Registration (MED0001194095)

General Medical Council UK: Full registration (4517405)

Invited International Speaker

2019 Invited Expert "Expert round table - management of foramen magnum stenosis in infants with Achondroplasia" ICCBH Saltzberg, Austria June 2019

2019 Invited paediatric expert "hEDS diagnostic criteria working group" EDS international.

2018 "Achondroplasia in Australia: growth and neurocognitive profiles" Achondroplasia Natural history expert meeting

2017 International Society of Prosthetics and Orthotics world congress, Cape Town, South Africa. Symposium on "Management and outcomes for children with congenital and acquired limb loss" (with the SCHN limb clinics teams)

2016 London Hypermobility Masterclass (95% positive feedback)

Invited National Speaker:

2018 Ehlers Danlos International Society Professionals day and Patient day Sydney and Perth

2017 Human Genetics Society Australia 41st ASM: Association of Clinical Geneticists

What do we do with all these hypermobile kids".

2014 Spring Meeting of the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists

Invited speaker on Joint Hypermobility Syndrome with Verity Pacey

2013 21st Annual Scientific Meeting of the Australasian Faculty of Rehabilitation Medicine Sydney 2013
Concurrent session: Sprains Strain and Pain: Growing Pains
Closing plenary: Hypermobility – To move or not to move (with Dr Tan, A/Prof Nicholson and Verity Pacey)
2011 Annual meeting of the International Society of Prosthetics and Orthotics Australia.
Hamblin N and **Tofts L**. C-Leg Improves function and quality of life in an adolescent traumatic transfemoral amputee (*platform*)

Research Activity – H index 9.

Papers in peer reviewed journals:

Pate, J.W.; Hancock, M.J.; Tofts, L.; Epps, A.; Baldwin, J.N.; McKay, M.J.; Burns, J.; Morris, E.; Pacey, V. Longitudinal Fibular Deficiency: A Cross-Sectional Study Comparing Lower Limb Function of Children and Young People with That of Unaffected Peers. *Children* **2019**, *6*, 45. <https://doi.org/10.3390/children6030045>

Lesley L Nicholson, Roger D. Adams, Louise **Tofts** and Verity Pacey (2017). Physical and Psychosocial Characteristics of Current Child Dancers and Nondancers With Systemic Joint Hypermobility: A Descriptive Analysis. *J Orthop Sports Phys Ther* 2017;47(10):782-791. Epub 4 Sep 2017. <https://doi.org/10.2519/jospt.2017.7331>.

Louise **Tofts**, Sandeep Das, Felicity Collins and Karen L.O. Burton (2017). Growth Charts for Australian children with Achondroplasia. *Am J Med Genet*. Online early 2017; 9999: 1-12. DOI: 10.1002/ajmg.a.38312

Mark C. Scheper, Lesley L Nicholson, Roger D. Adams, Louise **Tofts** and Verity Pacey (2017). The natural history of children with joint hypermobility syndrome and Ehlers Danlos Hypermobility type: a longitudinal cohort study. *Rheumatology*. Online early DOI 10.1093/rheumatology/kex148

Scheper MC, Pacey V, Rombaut L, Adams R, **Tofts L**, Calders P, Nicholson LL and Engelbert RHH (2017). Generalised Hyperalgesia in children and adults diagnosed with Ehlers Danlos Hypermobility type: A discriminative analysis. *Arthritis Care and Research*. Online early DOI 10.1002/acr.22998

Wigg, Kimberly, **Tofts Louise**, Benson Suzanne and Porter Melanie (2016). The Neuropsychological function of Children with Achondroplasia. *American Journal of Medical Genetics* online early

Pacey, V, **Tofts, L**, Adams, R., Munns, C., Nicholson, L (2015). Quality of Life prediction in children with joint hypermobility syndrome. *J. Paed Child Health*. 51(7), 689-95.

Pacey, V, **Tofts, L**, Wesley A, Collins FC and Singh-Grewal D (2015). Joint hypermobility syndrome: a review for clinicians. *J. Paed Child Health*. 51(4), 373-80.

Pacey, V, **Tofts, L**, Adams, R., Munns, C., Nicholson, L. (2015), Joint Hypermobility Syndrome subclassification in paediatrics: a factor analytical approach. *Arch Dis Child* 100(1) 8-13

Pacey, V, **Tofts, L**, Adams, R., Munns, C., Nicholson, L (2014). Proprioceptive acuity into knee hypermobile range in children with joint hypermobility syndrome. *Pediatric Rheumatology Online Journal*. 12(8), 40.

Tofts LJ and Hamblin N (2014). C-Leg improves function and quality of life in an adolescent traumatic trans femoral amputee – a case study. *Prosthetics and Orthotics International*. 38(5), 413-417.

Pacey, V, **Tofts, L**, Adams, R., Munns, C., Nicholson, L (2013). Exercise in children with joint hypermobility syndrome and knee pain: a randomised controlled trial comparing exercise into hypermobile versus neutral knee extension. *Pediatric Rheumatology Online Journal*. 11(1), 30.

Tofts LJ, Elliott EJ, Munns C, Pacey V, Sillence DO. The differential diagnosis of children with joint hypermobility: a review of the literature. *Paediatric Rheumatology*. 2009 Jan 5;7:1.

Tofts, LJ. Stanley, CS. Barnett, TG and Logan, JG. Knee joint function and the energy cost of level walking in soccer players. *British Journal of Sports Medicine*. 1998; **32(2)**:130-133.

Presented posters, abstracts and platform sessions:

Louise Tofts, Emma Siegal, Roger Adams, Leslie Nicholson and Verity Pacey. Anxiety and Depression in Australian children and adolescents with Joint Hypermobility Syndrome.

Verity Pacey, **Louise Tofts**, Roger Adams and Leslie Nicholson. Quality of life of children with JHS/EDS-HT: who will decline over 18 months. *Ehlers-Danlos Society 2016 International Symposium, New York*.

Nicholson, L., Pacey, V., Tofts, L., Munns, C., Adams, R. (2014). Signs and symptoms of foot and ankle dysfunction in children with joint hypermobility. *Journal of Foot and Ankle Research*, 7 (Suppl 1).

Pacey, V, **Tofts L**, Adams R and Nicholson L. Comparison of quality of life of children with Joint Hypermobility Syndrome, Charcot-Marie-Tooth disease and the general Australian paediatric population. *Abstract 8*

Pacey, V, **Tofts L**, Adams R, Munns C and Nicholson L. A RCT comparing two different exercise programmes for children with joint hypermobility syndrome (JHS) and knee pain. *Abstract 10*.

21st Annual Scientific Meeting of the Australasian Faculty of Rehabilitation Medicine, 2013

Pacey, V, **Tofts L**, Adams R, Munns C and Nicholson L. The fatigue experience of children with joint hypermobility syndrome: A child and parent perspective. *Internal Medicine Journal* 2013; 43 (suppl. 2) 7-8 RHPA 5 *54th Annual Scientific Meeting of the Australian Rheumatology Association, 2013*

Pacey, V, **Tofts L**, Adams R, Nicholson L and Munns C. Exercise Programmes for children with joint hypermobility syndrome and knee pain: a randomised controlled trial. *Internal Medicine Journal* 2012; 42 (suppl. 1) 36-38 RHPA P1 *54th Annual Scientific Meeting of the Australian Rheumatology Association, 2012*

S Das, F Collins and **LJ Tofts**. Head circumference for age curves in Australian boys with Achondroplasia and the association between head circumference and cervicomedullary compression.

S Das, F Collins and **LJ Tofts**. Descriptive Height, Weight and BMI for age charts in Australian boys with achondroplasia.

Posters at the 10th Meeting of the International Skeletal Dysplasia Society 2011

Paget SP and **Tofts LJ**. Growth plate injury due to meningococcal disease in childhood: a cause of delayed limb deformity impacting on orthopaedic and prosthetic management. (*poster*)

Tofts L and Farid M. The role of antenatal counselling at the time of diagnosis of congenital limb loss. (*poster*)

Presented at the Annual meeting of the International Society of Prosthetics and Orthotics Australia 2011

LJ Tofts, EJ Elliott, C Munns, V Pacey and DO Sillence. The differential diagnosis of children with joint hypermobility: a review of the literature *Paediatric Rheumatology* 2008, 6(Suppl 1):P156

LJ Tofts, S Hayden, MC Waugh. Effect of Botulinum Toxin type-A (Botox®) on neck pain and craniocervical headaches caused by trapezius spasm in a child with generalised joint hypermobility resulting from Noonan's Syndrome.

Paediatric Rheumatology 2008, 6(Suppl 1):P174

Posters at the Paediatric Rheumatology European Society meeting, London UK 2008

T.G. Barnett, J.G. Logan, Clare. S. Stanley and **Louise Tofts**. Energy cost of walking in soccer players. *J. Physiol.* 1995; **487**: 63P *Poster at the physiological society meeting, Cork, Ireland 1995*

Current projects:

"The clinical characteristics of children with joint hypermobility and their relationship to adverse outcomes" 5-year cohort study. data collection complete, 5 full publications, 2 further papers in draft.

"Effect of energy returning sport prosthesis on physical activity participation and quality of life" submitted

"Changes in physical function of young persons with longitudinal fibular deficiency" submitted

Principal Investigator, Visorotide for Achondroplasia (BMN 111-901, 111-301, 302 and 111-206)

Scholarships and Grants:

2017 RACP project grant \$10, 000 (for limb projects)

2014 Zimmer grant \$10, 000 (for hypermobility projects)

2012 Australian Rheumatology Association project grant \$ 15, 000 (for hypermobility projects)

2006 Clancy-Donald fellowship \$ 30,000 for a 12 month clinical sports medicine fellowship