



Craniofacial Society of Great Britain and Ireland

A Society for the study of Cleft Lip and Palate and other Craniofacial Anomalies



ANNUAL SCIENTIFIC CONFERENCE

To inspire, to inform

7th – 9th April 2014
Keble College, Oxford

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Spires Smiles is an independent, voluntary, non-profit organisation set up to support the Spires Cleft Centre at Salisbury NHS Foundation Trust and the patients and families who are treated there. Their aim is to raise awareness of cleft and raise funds within our local community. Over the next few months Spires Smiles will have a summer barbeque for all the families cared for by the team, have sponsored events including the "2014 kilometres challenge" and will continue to procure medical equipment requested by the team.



Rose Medical Solutions Ltd. design and manufacture solutions to assist in the assessment, diagnosis and treatment of speech disorders. Their mission is to create affordable, effective and reliable technology that can be used by clinicians and home users alike.

Starting with the first Kent Anemometer some 24 years ago, Rose Medical Solutions, in collaboration with the University of Kent, has a long history of creating technology for use in speech and language therapy.

The company recently announced the release of the Nasality Microphone, a low cost device that detects nasal and oral acoustic energy to provide a measure of nasality.



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President's Opening Address

I am delighted to welcome everybody to Oxford University for the 2014 Annual Scientific Conference of the Society. It's the second time the conference has come to Keble College and I hope the recently improved facilities should be noticeable to those who came in 1998.

Keble was founded in 1870 and is now one of the largest colleges in the University. It has many famous alumni and has some beautiful buildings designed by William Butterfield in a neo-gothic style. Take time to enjoy the surroundings and explore the architecture.

The Society has been holding Annual Scientific meetings since the mid 1980's. Jane Russell and Gill Stuffins have written a short history which has been included in the programme. I understand one of our founder members Arnold Huddart was able to contribute to the story. You will see we have grown from an informal group of interested individuals to a national multidisciplinary Society that represents all facets of cleft care.

We are extremely pleased to welcome our guest speakers and delegates who have come from around the world to be at the conference. Countries of origin include Brazil, New Zealand, Slovakia, Norway, Netherlands, Abu Dhabi and representation from all over the UK & Ireland. We believe the academic programme has something to offer the whole multidisciplinary team with enough time to network and meet up with old friends. We have an exciting social programme to entertain you in the evenings and hope you can both educate and enjoy yourself.

A handwritten signature in black ink, appearing to read 'Stephen Robinson'.

Stephen Robinson

President

Craniofacial Society of Great Britain and Ireland





Craniofacial Society of Great Britain and Ireland

History Of The Craniofacial Society Of Great Britain And Ireland (CFSGB&I)

In 1970 at East Grinstead, two Consultant Orthodontists, Arnold Huddart (based in Stourbridge in the West Midlands) and Denis Glass (East Grinstead) held a meeting concerned primarily with the treatment of cleft lip and palate. Yearly meetings involving orthodontists and maxillofacial and plastic surgeons followed, but in the late 70's the important role of speech therapists was recognised and they were also invited to attend.

Meetings continued on this basis and a successful international meeting presided over by Arnold Huddart was held in Birmingham in July 1983. Then in April 1985, a meeting was held in Wolverhampton to discuss the future of the Society. At this meeting there was considerable discussion about the name but those present voted for 'The Craniofacial Society of Great Britain A Society for the Study of Cleft Lip and Palate and other Craniofacial Anomalies.' ('and Ireland' was added in 1999). The issue of the Society's name was discussed again at the AGM in 1997 but the vote resulted in no change.

The logo of the Society depicts the tree of knowledge with the motto *Dies Diem Docet* (The day teaches the day) i.e. Education is never complete.

A formal society and membership

In 1985 when the Society was formally established with a constitution, the main categories of membership were orthodontics, plastic surgery, oral and maxillofacial surgery and speech & language therapy with a few members from other specialities, for example paediatric surgery, neurosurgery, research and morphoanalysis. A rotation of posts to ensure representation from the four main specialities was established on the CFS Council. In 1990 it was agreed that members from the other specialities group could also be nominated and stand for office and 'Other' became incorporated into the rotation. Today, as can be seen on the website, the 'Other' group includes many more professionals involved in the cleft palate/craniofacial field. Following CSAG implementation and the centralisation of services there was a decrease in the number of surgeons and an increase in nurses and psychologists. The nurses were originally part of 'Other' but their numbers reached a critical mass and they have had specific representation on Council since 2003. In 2011 (with effect from 2015) it was agreed that the categories of Maxillofacial Surgeon and Plastic Surgeon would be combined to the single category of Cleft Surgeon for the purposes of Council rotations.

A close association was maintained with CLAPA. In 1995, it was agreed that the National Secretary of CLAPA could be co-opted as a member of the Society and given financial assistance to attend meetings at the discretion of the President.

The Secretariat

A pivotal role in the development of the Society was played by Kathleen Randle, P.A. to Arnold Huddart. She had taken on the management and organisation of the Society from its inception and when the Society was formalised in 1985 became Membership Secretary, a role she continued to fulfil until 2002. Kath had an encyclopaedic knowledge of the Society, did most of the background administrative work and was an invaluable support to successive presidents and honorary secretaries. She supported the Society from the days of communication by letters requiring stamps through to the digital age. Following Kath's retirement, her loss was felt by a greater

burden being placed on the Honorary Secretary and other Officers. Finally in 2006 office facilities and a part time secretariat hosted by the Royal College of Surgeons of England was established.

Specific/Special Interest Groups (SIGs)

The Speech & Language Therapy (SLT) SIG was set up in 1987 and held one of its meetings each year immediately prior to the CFS Annual Scientific Meeting. The venue was close but usually different due to expense. From 1990 the CFS provided some financial assistance and from 1995 began to provide the lecture hall and audiovisual facilities for SLT meetings. Subsequently other speciality groups developed SIGs and SIG meetings now mark the opening day of the CFS Meeting with 8 taking place in Birmingham in 2013. This represents a considerable expense and logistical nightmare for the President but the Society recognises the importance of and valuable contribution of these groups. In addition the CFS helps SIGs to secure guest speakers at their meetings.

Specialities working together

The CFS has always been about more than an annual conference. The different specialities have met together in subcommittees to work on audit and research. The Audit Group produced a minimum data set for cleft audit. More recently the Society has funded audit and research workshops.

CARE (Craniofacial Society Anomalies Register) was instigated in 1989 as an initiative to record the births of children with craniofacial anomalies. Once again a multi disciplinary committee, funded by CFS, was set up to oversee CARE. In subsequent years paper submissions to the register were replaced by electronic data and CARE became CRANE which is now located in the Clinical Effectiveness Unit at the Royal College of Surgeons of England.

Over the years, when funds allowed, the Society has given grants for research and provided funding to assist members in attending international and its own conferences. CFS has also funded training initiatives for SLTs and Cleft Nurse Specialists. In June 1999, the CFS became a founder member of the Healing Foundation with representation on its Board of Trustees and also its Research Council. This has ultimately led to the Cleft Collective, the world's largest cleft lip and palate research programme in addition to other major initiatives which also relate to cleft and craniofacial anomalies.

The role of President has become much more than organising the annual conference. In 1996, the Society was asked to provide written evidence to the Clinical Standards Advisory Group (CSAG). The submission highlighted the interdisciplinary nature of CFS and its role in acting as the forum for the presentation and evaluation of British research and audit in this field. Subsequently the Society came to be represented in various NHS bodies and to be consulted for advice at government level and by the media.

From its inception as an informal group which ran annual meetings, the Society has grown in numbers and stature. It has developed to become the national professional organisation for cleft health care professionals promoting the highest standards of care.

Jane Russell & Gill Stuffins January 2014



Craniofacial Society of Great Britain and Ireland

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Annual General Meeting

The annual general meeting of the Craniofacial Society of GB & Ireland will be held on Tuesday 8th April between 16.45–17.45, in the O'Reilly Theatre at Keble College, Oxford. An agenda and minutes for the 2013 AGM and the council meeting from November 8th 2013 will be circulated to members beforehand. Elections will be held for the President elect for 2017 and for a new Honorary Secretary.

The 2013 - 2014 CFS council includes the following members and officers of the Society

Stephen Robinson – President
Jackie Smallridge – Paediatric Dentistry, Joint Vice President Elect
Kate le Maréchal – Psychology, Joint Vice President Elect
Helen Extence – Speech & Language Therapy
Karine Latter – Nursing
Rona Slator – Immediate Past President
Joyce Russell – Honorary Treasurer
Grant Davies-Ratcliff – Secretariat Manager

Future conferences

2015: Royal College of Physicians, London, April 15-17th
2016: The East Midlands Conference Centre, Nottingham, April 20-22nd
2017: 13th International Congress, Chennai, India, November 8-11th
2021: 14th International Congress, Edinburgh, June



Craniofacial Society of Great Britain and Ireland

Monday 7th April 2014

09:30-09:35	Conference welcome from Stephen Robinson, President
09:35-10:20	Update on the Genetics of OFC: Are we there yet? Professor Peter Mossey <i>University of Dundee</i>
10:20-11:00	Free papers
11:00-11:30	Coffee
11:30-12:15	Cleft Care in South America Professor Nivaldo Alonso <i>São Paulo University</i>
12:15-13:00	Free papers
13:00-14:00	Lunch
14:00-14:45	Saying words and doing talk: Speech development and speech intelligibility in a conversational context Professor Sara Howard <i>University of Sheffield</i>
14:45-15:30	Free papers
15:30-16:00	Tea
16:00-17:20	Arnold Huddart Medal Presentations
17:20	Close
18:30 – 20.00	Drinks reception at the Museum of Natural History

Tuesday 8th April 2014

09:00-09:45	Craniofacial Analysis for forensic identification and archaeological investigation Professor Caroline Wilkinson <i>Dundee University</i>
09:45-10:30	Is the approach to a Cleft Rhinoplasty any different? Mr Michael Cadier <i>Salisbury Foundation Trust</i>
10:30-11:00	Coffee
11:00-11:40	Managing the Adult Pathway in Cleft Care Mr A Currie, Mr G Kidner, Mr S Popat
11:40-13:00	Free papers
13:00-14:00	Lunch
14:00-15:00	Cleft Care UK 2010-2012 – The Results Cleft Collective - Bristol
15:00-15:15	BMP-2 for Alveolar Bone Grafting in Cleft Patients Professor Nivaldo Alonso
15:15-15:30	Free papers
15:30-16:00	Tea



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16:00-16:10	Superheroes Stephanie Jalland – Hoodwink Theatre
16:10-16:40	Towards Understanding the brain mechanisms of Parenting; Insights from cleft lip infants Morten Kringelbach Oxford University
16:40-16:45	Presentation of prizes
16:45-17:45	Craniofacial Society Annual General Meeting
17:45	Close
19:00-19:45	Pre-dinner drinks
20:00-23:00	Gala dinner in the Grand Hall, Keble College with live entertainment
23:00	Bar

Wednesday 9th April 2014

Special Interest Groups

09:30-12:30	Managers/Co-ordinators Nursing Orthodontics Paediatric Dentistry Psychology Speech <i>Surgery Live surgical demonstrations at the John Radcliffe Hospital</i>
10:15-11:30	Coffee
12:30-13:30	Lunch
13:30-16:00	Managers/Co-ordinators Nursing Orthodontics Paediatric Dentistry Psychology Speech <i>Surgery Live surgical demonstrations at the John Radcliffe Hospital</i>
14:45-15:30	Tea
16:00-16:30	Installation of new President
16:30	Close of Conference



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Invited Speakers

Professor Peter Mossey

University of Dundee

Update on the Genetics of OFC: Are we there yet?

Peter Mossey is Professor of Craniofacial Development and Dentofacial Orthopaedics, University of Dundee and Honorary Consultant in Orthodontics, Tayside University Hospitals Trust. Currently Associate Dean for Research University of Dundee Dental School and Director, World Health Organisation (WHO) Collaborating Centre for Craniofacial anomalies (CFA).



Peter was officially nominated in March 2000 by WHO as one of four experts in the world for the purposes of co-ordinating global research in craniofacial birth defects. He was offered a half time personal assistant and 10% current salary from June 2000 to ensure protected time for this project. On 23rd August 2004 the Unit of Dental and Oral Health at the University of Dundee was designated a "WHO Collaborative Centre for Public Health Issues on Congenital Anomalies and Technology Transfer" in recognition of the research work on Cleft lip and palate and other Craniofacial anomalies. WHO collaborative status renewed in 2008 and 2012. In 2009 Peter was appointed section Editor for Genetics to the Board of Editors of the Cleft Palate-Craniofacial; the premier international journal in the field of Cleft lip and palate and other Craniofacial anomalies.

In Barcelona 2011, Peter was invited to Chair the Craniofacial Anomalies Taskforce to contribute to the Global Oral Health Inequalities Research Agenda (GOHIRA) which reported to the International Association of Dental Research IADR.

In June 2012 at the Annual meeting of the IADR, a new Global Network was established and in August 2012 Peter was appointed Secretary to the Global Health Inequalities Research Network (GOHIRN) group.

Professor Nivaldo Alonso

São Paulo University

Cleft Care in South America

Professor Nivaldo Alonso graduated in Medicine from Escola Paulista de Medicina (1978) and obtained his PhD in Clinical Surgery through the Faculty of Medicine of the University of São Paulo (1992).

He obtained his habilitation at Faculty of Medicine of the University of São Paulo (FMUSP) in 2002.

He was a Collaborating Professor at the Faculty of Medicine USP from 2005 to 2009. He gained his Associate Professorship for the Plastic Surgery course unit at the Faculty of Medicine at USP in 2009, for which he remains responsible. He was the president of the Brazilian Society of Craniomaxillofacial Surgery for two terms, 2000-2002 and 2006-2008. Since 2004 he has been the Medical Director at the Non-Governmental Organization Operation Smile.

Since October 2008 Professor Alonso has held the position of Coordinator of the Craniomaxillofacial Surgery Team at the Craniofacial Anomalies Rehabilitation Hospital in Bauru - USP (HRAC - Centrinho). Nivaldo has done over 240 presentations at national and international conferences and symposia. Nivaldo has over 170 full articles published in national and international journals and has written over 50 chapters in published books.

He has wide experience in surgery with emphasis in Plastic Surgery, in which he is a specialist through the Brazilian Society of Plastic Surgery. He also has the title of specialist in the Craniomaxillofacial Surgery through the Federal Council of Medicine.



Professor Sara Howard

Professor of Clinical Phonetics

Department of Human Communication Sciences

University of Sheffield, UK

Saying words and doing talk: Speech development and speech intelligibility in a conversational context

Sara Howard is Professor of Clinical Phonetics in the Department of Human Communication Sciences at the University of Sheffield. After a first degree in English and a Masters in Linguistics, she went on to complete a degree in speech and language therapy and then a PhD in clinical phonetics, traversing the territory from Arts to Sciences en route.



Her main research interests lie in the area of the phonetics/phonology interface in speech development and developmental



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speech impairments (especially cleft lip and palate). Her work explores speech output in different contexts, comparing single word production and sentence repetition in formal assessment with the production of longer utterances in real conversational settings. She recently completed an ESRC Research Fellowship on "Connected speech and word juncture in typical and atypical speech development", which allowed her to indulge this interest, unfettered by teaching or management responsibilities, for two glorious years.

Her most recent books are *The Blackwell Handbook of Clinical Linguistics* (2008), co-edited with Martin Ball, Mick Perkins and Nicole Müller, and *Cleft Palate Speech: Assessment and Intervention* (2011), co-edited with Anette Lohmander, Karolinska Institute, Stockholm.

Sara is currently President of the International Clinical Phonetics and Linguistics Association and a member of the Research Excellence Framework sub-panel for Dentistry, Nursing and Allied Health Professions.

She is Programme Director for the Postgraduate Certificate in Cleft Palate Studies and for the Postgraduate Diploma and Masters in Cleft and Speech at Sheffield, and has supervised research students working on speech production in cleft palate in Arabic, Amharic and Farsi.

Professor Caroline Wilkinson

Dundee University

Craniofacial Analysis for forensic identification and archaeological investigation

Caroline is Professor of Craniofacial Identification in the Centre for Anatomy & Human Identification (CAHID) at the University of Dundee. CAHID won a Queens Award for Higher Education in 2013.

Her expertise is craniofacial identification and anatomy and her forensic casework includes skeletal interpretation, facial recognition, facial depiction from skeletal remains and craniofacial superimposition. She is author of *Forensic Facial Reconstruction and Craniofacial Identification* and she was the first woman President of the International Association of Craniofacial identification (IACI) in 2008.

Prof Wilkinson has also been involved in many archaeological investigations and her work is exhibited in museums around the world. She has also appeared in popular science TV programs such as *History Cold Case*, *Meet the Ancestors*, *Secrets of the Dead* and *Mummies Unwrapped*. She has the RSE Senior Award for Public Engagement and delivered the 2013 RSE Christmas Lecture.



Mr Michael Cadier

Consultant Plastic Surgeon
Salisbury NHS Foundation Trust

Is the approach to a Cleft Rhinoplasty any different?

Michael's undergraduate training was at Oxford University and St Thomas's Hospital in London. He qualified in 1986 and trained as a plastic surgeon undertaking postgraduate training in London, Salisbury and Bristol, with overseas fellowships in France and Belgium. He completed his training in 1998 obtaining a Master of Surgery degree with a thesis on the 'laser treatment of facial vascular malformations'.

He was appointed to his current consultant post in 1997 and his main surgical interests are in cleft lip and palate care and aesthetic surgery. He is actively involved in training the next generation of surgeons and has previously been both the Clinical Director of the Spires Cleft Centre and Head of the Salisbury Plastic Surgery department.

He is currently an examiner for the Royal College of Surgeons (FRCS Plast), sits on the Cleft Training Interface group, is a member of the UK delegation for the CEN in Cosmetic Surgery (aiming to provide European wide regulation of the industry), and is President Elect of The British Association of Aesthetic Plastic Surgeons.

He has visited many overseas hospitals to improve his knowledge base and for 15 years undertook annual charity missions to rural Pakistan operating on children with severe facial deformities and post burn contractures. His academic interests include the measurement of aesthetic outcomes in both Cleft and Aesthetic Surgery.





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Morten Kringelbach

Aarhus University, Denmark
Oxford University



Towards understanding the brain mechanisms of parenting; Insights from cleft lip infants

Morten Kringelbach is Director of Hedonia: Trygfonden Research Group, which is a unique transnational research collaboration between Oxford and Aarhus universities. He holds a dual appointment as Senior Research Fellow at the Department of Psychiatry, University of Oxford, and Professor of Neuroscience at Aarhus University, Denmark. In addition, he is also an Extraordinary JRF (Junior Research Fellow) at The Queen's College, Oxford.

The main focus of his research is to understand the functional neuroanatomy of human conscious and unconscious processing; in particular the aspects related to pleasure, emotion, learning and reward processing. While pleasure is clearly at the heart of what makes us human, at the same time it is also one of the most important factors keeping us from staying healthy, such as the devastating effects of the lack of pleasure found in depression and other affective disorders. A special focus of his research is therefore on understanding hedonic processing in the human brain, which could in time help to treat these disorders more effectively.

His latest book, *The Pleasure Center* (OUP, 2009), brings together much of his past research to provide a novel synthesis of these important issues for the general public. In addition to his scientific research, he also has a keen interest in linking art and science. He has an on-going collaboration with the Scottish artist Annie Cattrell with whom he has made artworks and sculptures exploring the unseen inner spaces of the living human body and brain.

CLEFT CARE UK CFSGB&I – THE RESULTS

Andy Ness, Martin Persson, Tim Jones, Rana Al-Ghatam, Debbie Sell, Liz Albery, Sue Mildinhall, Andrea Waylen, Jonathan Sandy

Andy Ness

Andy Ness is the Principal Investigator on the Head and Neck 5000 clinical cohort study and the Cleft Care (UK) cross-sectional survey. He qualified in Medicine in 1986 from Nottingham University and was a Wellcome Training Fellow in Clinical Epidemiology at Cambridge from 1993 to 1997. Andy was appointed as a Senior Lecturer in Epidemiology in 1997 in the Department of Social Medicine at the University of Bristol. He moved to the Department of Community-based Medicine to become a co-Director of the Avon Longitudinal Study of Parents and Children (ALSPAC) in 2003 and was a member of the seven person executive that ran ALSPAC until 2012. He was appointed to a Chair in Epidemiology in the School of Oral and Dental Sciences at the University of Bristol in January 2007. Andy is the head of the Lifecourse Epidemiology and Population Oral Health Research Group. He has interests in early life exposures, nutrition, physical activity, obesity, cardiovascular risk and in cleft lip and palate and head and neck cancer.



Andy has published over 200 papers in peer-reviewed journals (his H index is 48). He has been applicant or co-applicant on 45 grants worth a total of over £40 million. Andy is also Director of the NIHR Biomedical Research Unit at the University Hospitals Bristol NHS Foundation Trust and the University of Bristol and the in Nutrition, Diet and Lifestyle.



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Main Programme

Monday 7th April 2014

09:30-11:00	SESSION ONE: GENETICS/EARLY CARE CHAIR: NICHOLA HUDSON
09:30-09:35	Introduction by Stephen Robinson, President
09:35-10:20	LECTURE: UPDATE ON THE GENETICS OF OFC: ARE WE THERE YET? Professor Peter Mossey University of Dundee
10:20-11:00	5 free papers
10:20	Improved Diagnostic Outcomes in Craniofacial Surgery by use of Next-Generation DNA Sequencing Vickram Sharma, Aimee Fenwick, Mia Brockop, Stephen Twigg, Simon McGowan, Julie Phipps, 500 Whole-Genome Sequences (WGS500) Consortium, Jacqueline Goos, Irene Mathijssen, Sally Lynch, Dylan Murray, John Mulliken, Angela Brady, Sue Tomkins, Elizabeth Sweeney, Louise Wilson, Owase Jeelani, Deirdre Cilliers, Jenny Morton, Peter Noons, Hiroshi Nishikawa, David Johnson, Steven Wall, Robert Maxson, Tracy Lester, Andrew Wilkie
10:28	Developing a clinical pathway for patients with 22q11 deletion syndrome Sharon Baker, Helen Extence, David Drake
10:36	4D Data Analysis of Facial Animations For Craniofacial Surgery Assessment X Ju, A Ayoub and B Khambay
10:44	Fetal MRI Allows Precise In Utero Diagnosis of a Soft Palate Cleft – Influencing Clear Cut Antenatal Care by Clinical Nurse Specialists Jane Sibley, Fintan Sheerin, Tim Goodacre
10:52	Can we improve our post-operative analgesia following cleft lip and palate repair? Dr Carolyn Smith, Ms Linda Paton, Ms Orla Duncan
11:00-11:30	Coffee
11:30 – 13:00	SESSION TWO: SURGERY CHAIR: TIM GOODACRE
11:30-12:15	LECTURE: CLEFT CARE IN SOUTH AMERICA Professor Nivaldo Alonso. São Paulo University
12:15-13:00	5 free papers
12:15	Vestibular Dysfunction in Craniofacial Abnormalities – Focus on Apert Syndrome Mark Perera, Heide Mills, John Veness, Ewa Raglan
12:23	Outcomes of importance to parents and children: Qualitative findings from the mOMEnt study S Tierney, K O'Brien, N Harman, R Sharma, C Madden, P Callery on behalf of the mOMEnt team
12:31	Association of Width of Cleft Palates with Surgical & Functional Outcomes – A 6-Year Experience Muhammad Asim Bashir, Reza Alamouti, Fiona Perry, Norma Timoney
12:39	A technique for assessing velar muscle position and function on intra-oral examination Felicity V Mehendale
12:47	A cross-sectional self report questionnaire study measuring the effect of primary cleft repair on parental bonding in children born with cleft lip and/or palate LK Wharton, A Zeffert, S Burton, F Franks, L Minerviro, H Swain, T Ahmad, JD Kiff
13:00-14:00	Lunch
14:00 – 15:30	SESSION THREE: SPEECH & LANGUAGE CHAIR: GINETTE PHIPPEN
14:00-14:45	LECTURE: SAYING WORDS AND DOING TALK: SPEECH DEVELOPMENT AND SPEECH INTELLIGIBILITY IN A CONVERSATIONAL CONTEXT Professor Sara Howard University of Sheffield



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14:45-15:30	5 free papers
14:45	Speech outcomes by cleft type: 3 years of data across four cleft centres Stephanie van Eeden, Melanie Bowden, Lorraine Britton, Gillian Cairns, Lisa Crampin, Siobhan McMahon, Jenny Nayak
14:53	A novel way of assessing velopharyngeal insufficiency in the paediatric cleft population Andrew Gardner, David Wynne, Craig Russell, Arup Ray, Lisa Crampin, Lindsay Campbell Mark Devlin
15:01	The impact of late cleft palate repair on speech development: a retrospective analysis of 39 consecutive cases over year period. MC Swan, N Pancewicz, D Sell, M Pinkstone, G Thorburn, P Morris, BC Sommerlad, L Kangesu
15:09	Speech Therapy and Hearing Loss: is there a link for cleft palate patients? Sinéad Davis and Sharon Baker
15:17	An investigation of factors influencing speech articulation outcomes aged 5 years Lorraine Britton
15:30-16:00	Tea
16:00 – 17:20	SESSION FOUR: ARNOLD HUDDART MEDAL CHAIR: ANDREW CURRIE
16:00-17:20	Arnold Huddart Medal Presentations 8 free papers
16:00	Fistula incidence after primary cleft palate repair – a meta-analysis of 9,444 patients. Joseph Hardwicke, Bruce Richard
16:10	The emerging cleft palate syndrome associated with SATB2 mutations Rita M Ibitoye, Jill Clayton-Smith, Fiona Connell, Sally A Lynch, Helena Malmren, Shane McKee, Sarju G Mehta, Ann Nordgren, Fiona Stewart, Margo Whiteford, Helen Firth, David FitzPatrick, DDD Study, Usha Kini
16:20	A comparison of non-airway interventions required in isolated cleft palate patients with and without Robin Sequence J Steele, C Florin Villar, P Morris, G Thorburn, B Sommerlad, J Hughes, R Chorbachi, L Harding, L Cochrane, P Cunnington, J Herod, M McEvoy, S Nambiar, F Abel, L Kangesu
16:30	First results from a new Cleft Aesthetic Outcome Assessment System Husam Bella, Tri Tat, Yashashwi Sinha, Adam Gwozdz, Katy Wallis, Bruce Richard
16:40	Peer Assessment Rating (PAR) of cleft patients treated within a regional cleft centre in the United Kingdom. C Dunbar, G Kidner, M Cobourne
16:50	Multidisciplinary Aspects of 104 Patients with Pierre Robin Sequence Treated at the Oslo Cleft Lip and Palate Team Charles Filip, Kristin Billaud Feragen, Els-Marie Andersson, Nina Lindberg, Jorunn Skartveit Lemvik, Mitra Rashidi, Hans Erik Høgevold, Michael Matzen
17:00	A study to evaluate the effectiveness of Pre Surgical Orthopaedics in reducing the alveolar cleft width in UCLP patients T Macdonald, J Green, B Patel and N Hay
17:10	A retrospective study to analyse the relationship between social deprivation and 5 year speech and language outcome. Mr J Barry, Dr Butterworth, Mr Hodgkinson
17:20	Close
18:30-20:00	Welcome reception to be held at the Museum of Natural History



Craniofacial Society of Great Britain and Ireland

Tuesday 8th April 2014

09:00 – 10:30	SESSION FIVE: FACIAL RECONSTRUCTION CHAIR: SANDIP POPAT
09:00-09:45	LECTURE: CRANIOFACIAL ANALYSIS FOR FORENSIC IDENTIFICATION AND ARCHAEOLOGICAL INVESTIGATION Professor Caroline Wilkinson - Dundee University
09:45-10:30	LECTURE: IS THE APPROACH TO A CLEFT RHINOPLASTY ANY DIFFERENT? Mr Michael Cadier - Salisbury NHS Foundation Trust
10:30-11:00	Coffee
11:00 – 12:04	SESSION SIX: ADULT CLEFT CARE CHAIR: MICHAEL CADIER
11:00	Managing the Adult Pathway in Cleft Care Mr A Currie, Mr G Kidner, Mr S Popat
11:40	Does cleft osteotomy improve quality of life? K Tidbury, TR Flood, A Morton, S Stagnell, K French, J Burdett
11:48	Face-ism -Cultural bias in relation to facial shape DF Campbell, EH Nichols, D Graham
11:56	Cleft Repair in the Elderly Population – the South Wales Experience Serryth Colbert, Helen Extence, Shirley Williams, Adrian Sugar, David Drake
12:04 –13:00	SESSION SEVEN: PSYCHOLOGY CHAIR: ANGELA SHANLY
12:04	Patient and Parent Satisfaction – How to measure and report Dr Vanessa Hammond
12:24	Starting a family: the experience of parents with CL/P Nicola Marie Stock and Nichola Rumsey
12:32	Family Impact in Cleft Lip and Palate children in New Zealand John M D Thompson, Megan Sanders, Harriette van de Zee, Peter V Fowler
12:40	The Patient Voice – how to create effective patient involvement Becky Gowers and Rosanna Preston
12:48	Changing Faces Practitioners and Cleft Services- Outcomes for the first twelve months of a new NHS integrated post Orla Duncan, Felicity Mehendale, James Partridge, Elizabeth Noble, Sam Cheatle, Carolyn Wesson
13:00-14:00	Lunch
14:00 -15:30	SESSION EIGHT: RESEARCH FOCUS I CHAIR: GILES KIDNER
14:00	LECTURE: CLEFT CARE UK 2010-2012 – THE RESULTS Introduction: Andy Ness, Methods: Martin Persson. Structure (Appearance and models) Tim Jones & Rana Al-Ghatam, Speech: Debbie Sell, Liz Albery & Sue Mildinhal. Psychology: Andrea Waylen. Closing remarks and discussion: Jonathan Sandy
15:00	BMP-2 FOR ALVEOLAR BONE GRAFTING IN CLEFT PATIENTS Nivaldo Alonso
15:15	Use of the daVinci® Surgical Robotic System for posterior pharyngeal wall and palate surgery in the cleft patient - a feasibility study Khurram Khan, Tom Dobbs, Tim Goodacre
15:23	The Cleft Collective Cohort Studies: An update Kerry Humphries, Nicola Stock, Beate St Pourcain, Martin Persson, Yvonne Wren, Maggie Bailey, Nichola Rumsey, Jonathan Sandy



Craniofacial Society of Great Britain and Ireland

15:30	Tea
16:00 – 17:45	SESSION NINE: RESEARCH FOCUS II & CFS ANNUAL GENERAL MEETING CHAIR: STEPHEN ROBINSON
16:00-16:10	Stephanie Jalland of Hoodwink Theatre - Superheroes
16:10-16:40	LECTURE: TOWARDS UNDERSTANDING THE BRAIN MECHANISMS OF PARENTING; INSIGHTS FROM CLEFT LIP INFANTS Morten Kringelbach
16:40-16:45	Presentation of Prizes
16:45-17:45	Craniofacial Society Annual General Meeting
17:45	Close
19:00-19:45	Pre-dinner drinks
20:00-23:00	Gala dinner in the Grand Hall, Keble College with live entertainment
23:00	Bar

Wednesday 9th April 2014

Special Interest Groups to be held in the Sloane Robinson Building, Keble College		
Surgical Demonstrations to be held at the John Radcliffe Hospital, Academic Block, Lecture Theatre 1		
09:30-12:30	Nursing	Seminar Room 5
	Speech	The O'Reilly Theatre
	Paediatric Dentistry	Seminar Room 1
	Psychology	Seminar Room 3
	Orthodontics	Seminar Room 2
	Managers/Co-ordinators Surgery	Seminar Room 4
	Surgery	Lecture Theatre 1, Academic Block, John Radcliffe Hospital Oxford University NHS Trust
10:15-11:30	Coffee	
12:30-13:30	Lunch	
13:30-16:00	Nursing	Seminar Room 5
	Speech	The O'Reilly Theatre
	Paediatric Dentistry	Seminar Room 1
	Psychology	Seminar Room 3
	Orthodontics	Seminar Room 2
	Managers/Co-ordinators Surgery	Seminar Room 4
	Surgery	Lecture Theatre 1, Academic Block, John Radcliffe Hospital Oxford University NHS Trust
14:45-15:30	Tea	
16:00-16:30	Installation of new President	The O'Reilly Theatre
16:30	Close of Conference	



Oral Abstracts

Monday 7th April 2014 – 09:35

Update on the Genetics of OFC: Are we there yet?

Professor Peter Mossey - University of Dundee

Monday 7th April 2014 – 10:20

Improved Diagnostic Outcomes in Craniofacial Surgery by use of Next-Generation DNA Sequencing

Vickram Sharma, A Fenwick, M Brockop, S Twigg, S McGowan, J Phipps, 500 Whole-Genome Sequences (WGS500) Consortium, J Goos, I Mathijssen, S Lynch, D Murray, J Mulliken, A Brady, S Tomkins, E Sweeney, L Wilson, O Jeelani, D Cilliers, J Morton, P Noons, H Nishikawa, D Johnson, S Wall, R Maxson, T Lester, A Wilkie

Introduction: Craniosynostosis has a prevalence of ~1 in 2,200 and in ~21% of cases, a genetic cause is identified. This includes mutations of TWIST1 causing Saethre-Chotzen syndrome, typically presenting with coronal synostosis.

Methods: We performed whole-exome sequencing of 7 patients with non-syndromic bilateral coronal synostosis in whom all known gene tests were negative.

Results: Loss-of-function mutations in TCF12 (Transcription Factor 12) were found in 3 cases. Follow up Sanger sequencing identified 38 heterozygous TCF12 mutations in 347 unrelated samples, accounting for 32% and 10% of subjects with bilateral or unilateral coronal pathology. Thirteen cases arose de novo and significant non-penetrance was found, possibly related to haplotype. TCF12 and TWIST1 act synergistically in vitro and mice doubly heterozygous for loss-of-function mutations have severe coronal synostosis. Surgical trajectory of TCF12-mutation positive patients is more favourable than other genotypes and together with another disease gene (ERF), diagnostic outcomes have improved from 21% to 24%.

Conclusions: Mutations of TCF12 are a common cause of coronal synostosis. The post-operative course is uneventful. The TCF12-TWIST1 heterodimer is likely to regulate an embryonic tissue boundary in the skull. Molecular testing is indicated if mutational hotspots are negative and was rapidly translated as a national service after discovery.



Oral Abstracts

Monday 7th April 2014 – 10:28

Developing a clinical pathway for patients with 22q11 deletion syndrome

Sharon Baker, Helen Extence, David Drake

Aim: To determine the most effective surgical intervention for patients with 22q11 deletion syndrome as part of an integrated clinical pathway.

Method: A retrospective review of speech outcomes in patients with 22q11 deletion syndrome following surgical intervention was carried out in order to determine what would be the most efficient and effective intervention to improve resonance. We reviewed patients diagnosed with 22q11 deletion syndrome who had surgery between 1998 – 2013 in South Wales, surgery performed and post operative resonance.

Results: 22q11 patients with cleft palate had normal resonance by 5 from primary palate repair. Those with SMCP or non-cleft velopharyngeal dysfunction had required a pharyngoplasty +/- SMCP repair in order to achieve normal resonance/mild hypernasality. It was noted that those non cleft patients who had normal resonance at 5 but had not had a pharyngoplasty deteriorated by the age of 10 and required further surgery to improve their resonance.

Conclusion: As a result of the review we have devised a MDT clinical pathway for patients with 22q11.

Monday 7th April 2014 – 10:36

4D Data Analysis of Facial Animations For Craniofacial Surgery Assessment

X Ju, A Ayoub and B Khambay

Background: 4D imaging is a recent innovation of stereophotogrammetry. The method allows dynamic capture of facial animations at a rate of 60 3D frame/second; generating hundreds of 3D images. Analysis of the 3D image sequence has enabled dynamical assessment of the facial soft tissue following maxillofacial surgery. This study describes the process of "automatic landmark tracking" and presents a comprehensive approach for the analysis of facial animations.

Materials and Methods: This study was carried out on four groups of individuals; volunteers, patients with distorted animations due to cancer resection and on surgically managed cleft cases. The accuracy of automatic landmark tracking in relation to those digitised manually was investigated together with the reproducibility of facial expressions. Landmarks and facial surface based approaches were applied to evaluate the lip movements in terms of magnitude, speed and similarity.

Key Results: 4D imaging is a reliable method for the objective evaluation of facial animations Automatic tracking of landmarks across the 3D sequence of facial images was within 0.5mm accuracy. 4D capture has shown reproducibility of facial expressions. Cancer surgery decreased the magnitude of lip movements and reduced the speed of facial animations. Asymmetry of lip movements were detected in cleft cases.



Oral Abstracts

Monday 7th April 2014 – 10:44

Fetal MRI Allows Precise In Utero Diagnosis of a Soft Palate Cleft – Influencing Clear Cut Antenatal Care by Clinical Nurse Specialists

Jane Sibley, Fintan Sheerin, Tim Goodacre

Over the past 12 years the Oxford Spires Cleft Team has offered fetal MRI to all mothers with an ultrasound diagnosis of a cleft lip. This enables definitive in utero diagnosis of the presence or absence of a posterior (soft) cleft palate associated with this.

Alongside radiology and Consultant colleagues, the Clinical Nurse Specialist ensures appropriate referral, reads and understands the scan reports and discusses these and the implications with the parents to be.

Over the last 18 months the improved clarity and accuracy in interpretation of these scans and especially the precision of whether the posterior palate is cleft or non-cleft has been instrumental to the clinical nurse specialists in the ability to give specific antenatal advice pertinent to the infant, the parents and relevant professionals and neonatal units.

We present this consecutive series of 18 patients from the last 18 months, 6 of which fetal MRI completely changed the ultrasound diagnosis and critically the plan of postnatal care. In 17 out of 18 cases fetal MRI correctly predicted the degree of palatal involvement to include precise diagnosis of the soft palate.

We also discuss the dilemmas that fetal MRI scans can present.

Monday 7th April 2014 – 10:52

Can we improve our post-operative analgesia following cleft lip and palate repair?

Dr Carolyn Smith, Ms Linda Paton, Ms Orla Duncan

The aim of this audit was to determine whether oral morphine solution provided superior analgesia to codeine for patients following cleft surgery.

A two part questionnaire with patient demographics, type and duration of surgery, analgesia/local anaesthesia used intra-operatively, time to first feed and subsequent post-operative requirements was completed for all infants having surgery in our unit. The first part of the form was completed by the anaesthetist and the second part by the ward staff. For a period of three months oral morphine solution (0.2 mg/kg) was substituted for codeine (1mg/kg). All other parameters remained unchanged. The doses and frequency of analgesia required was recorded as well as parent and nursing staff satisfaction assessments.

The infants were more unsettled and felt to have poorer pain relief by the nursing staff when given oral morphine.

The oral morphine made the infants more sedated but for a shorter time such that it was difficult to get the infants to feed well and they were much more unsettled. The audit was stopped early as a result and analgesia reverted to codeine.



Oral Abstracts

Monday 7th April 2014 – 11:30

Lecture: Cleft Care in South America

Professor Nivaldo Alonso. São Paulo University

Monday 7th April 2014 – 12:15

Vestibular Dysfunction in Craniofacial Abnormalities – Focus on Apert Syndrome

Mark Perera, Heide Mills, John Veness, Ewa Raglan

Vestibular dysfunction is a little known but recognized feature which can be present in craniofacial abnormalities. This can cause a delay in the attainment of gross motor milestones. In Apert syndrome the imbalance is frequently attributed to the mechanical problems secondary to syndactyly. However, our experience suggests that a vestibular component often co-exists. This is not well recognized, poorly documented and scarcely treated.

We have retrospectively reviewed a cohort of patients presenting with imbalance and motor delay via the craniofacial audiology and balance clinic at Great Ormond Street hospital. Vestibular assessment suggests that this cohort frequently have vestibular hypofunction which can compensate with time.

We aim to increase awareness of this and advocate a high index of suspicion, early detection and thorough vestibular assessment with timely physiotherapy to rehabilitate patients and maximise their functional attainment.



Oral Abstracts

Monday 7th April 2014 – 12:23

Outcomes of importance to parents and children: Qualitative findings from the mOMEnt study

Stephanie Tierney, K O'Brien, N Harman, R Sharma, C Madden, P Callery on behalf of the mOMEnt team

Background: Most children with cleft palate (CP) experience otitis media with effusion (OME). However, what they and their parents consider to be important treatment outcomes are unclear.

Aims: To explore what children with a CP and their parents thought were important outcomes following treatment for OME.

Design: A qualitative study was conducted as part of a larger project to develop a set of core outcomes to be measured in future studies on OME in CP.

Data collection: Semi-structured interviews with 22 children and 43 parents were audio-recorded and transcribed verbatim. They were recruited from two cleft centres in England.

Data analysis: Framework analysis was used to develop codes and themes.

Results: Parents and children regarded hearing as a key outcome. However, they suggested that they would also look for an improvement in social (e.g. mixing with others) and psychological (e.g. self-confidence) aspects of the child's life. Parents mentioned the importance of improvements in education, whilst children wanted to 'fit in' with friends.

Conclusion: Findings show that although clinical outcomes are important to those affected by OME, consideration should also be given to wider psychosocial outcomes when assessing the effectiveness of treatment.

Monday 7th April 2014 – 12:31

Association of Width of Cleft Palates with Surgical & Functional Outcomes – A 6-Year Experience

Muhammad Asim Bashir, Reza Alamouti, Fiona Perry, Norma Timoney

Introduction: Cleft width and potential fistula formation may influence outcomes in children with clefts. We present data spanning 6 years, looking at the width of the palate at the hard-soft palate junction, the use of lateral release incisions, fistula rates and speech outcomes.

Methods: From 2005 onwards, 189 patients with all cleft types, were operated under the care of a single surgeon at the South Thames Cleft Service. Data relating to cleft diagnosis, width of cleft at the H-S junction, use of lateral release incisions, fistula rates, and CAPS-A speech outcomes were collected.

Results: After exclusions, 158 patients were categorized according to cleft width into the following groups –

1. < 5mm (n = 26)
2. 5-9.9mm (n= 72)
3. 10-14.9mm (n= 56)
4. >15mm (n= 4)

We found that Group 3 had the greatest need for further interventions in relation to speech outcomes and the necessity for further surgery. This correlated well with fistula of Pittsburgh types 3 & 4.

Conclusions: While some recommend children with a cleft width of >15mm undergo lateral release incisions, we found that lack of releasing incisions in the 10-14.9mm group correlated well with the presence of fistulae and the need for further interventions.



Oral Abstracts

Monday 7th April 2014 – 12:39

A technique for assessing velar muscle position and function on intra-oral examination

Felicity V Mehendale

Intra-oral examination forms an important part of assessment of velar function, in particular, the orientation of velar muscles, when planning potential velar surgery. However, patients may articulate a nasal /a/ with little velar movement or may show mainly contraction of the lateral pharyngeal walls (using palatopharyngeus) with little to no levator veli-palatini (LVP) contraction, making assessment of LVP orientation/position difficult.

Although velar movement and orientation of LVP, are best assessed on higher vowels, attempts to articulate a high vowel, often result in the tongue obscuring the examiner's view of the velum during conventional intra-oral examination. We describe a technique of intra-oral examination, using the endoscope to visualize the velum on higher vowels.

Patients undergoing VPI investigation underwent lateral videofluoroscopy+/-nasendoscopy. In addition, endoscopic intra-oral examination was recorded using the nasendoscope.

Compliance with endoscopic intra-oral examination was high, even in children who would not comply with nasendoscopy. Anatomical and functional differences on high and low vowels (/i/ and /a/) were well visualized. Greater evidence of palatopharyngeus contraction on /a/ and LVP contraction on /i/ were seen. Illustrative videos will be presented.

Conclusion: Endoscopic intra-oral examination is a quick, non-invasive, well-tolerated technique for evaluation of LVP position and is now incorporated in our VPI investigations.

Monday 7th April 2014 – 12:47

A cross-sectional self report questionnaire study measuring the effect of primary cleft repair on parental bonding in children born with cleft lip and/or palate

Laura Wharton, A Zeffert, S Burton, F Franks, L Minerviro, H Swain, T Ahmad, JD Kiff

The parent-infant bond is a key psychological process, with both short- and long-term implications for the child. Studies in the general population have demonstrated an impact of parents' postpartum psychiatric disorders on bonding, and it has been suggested that this may be more common for mothers of children with a cleft. Primary cleft surgery results in significant cosmetic and functional changes, with a potential impact on bonding. Clinical observation and audit data collected by Cleft.NET.East suggests that the surgery, and consequent appearance change, may subject parents to psychological distress that may raise the risk of postpartum psychiatric disorders.

We aimed to evaluate the impact of primary cleft surgery on parent-infant bonding and the relationship to psychological distress in both mothers and fathers.

The parents of infants born with a cleft lip with/ without cleft palate (external anomaly group) and with an isolated cleft palate (internal anomaly group) were investigated within a longitudinal correlational design. Validated and study specific self-report questionnaires were used to determine parent perspectives pre- and post-operatively.

We present the experiences of primary cleft surgery in our cohort, regarding perception of bonding, mood, anxiety, and cleft-specific data regarding satisfaction with appearance, feeding difficulties and thoughts and emotions about surgery.



Oral Abstracts

Monday 7th April 2014 – 14:00

Lecture: Saying words and doing talk: Speech development and speech intelligibility in a conversational context

Professor Sara Howard
University of Sheffield

Monday 7th April 2014 – 14:45

Speech outcomes by cleft type: 3 years of data across four cleft centres

Stephanie van Eeden, M Bowden, L Britton, G Cairns, L Crampin, S McMahon, J Naya

NorCleft is a quad-centre audit group consisting of the following Regional Cleft Centres: Scotland; Northern and Yorkshire; Trent; North West, Isle of Man and North Wales. An audit of speech outcomes by cleft type was carried out in 2013 and the results are presented here.

Participants: 586 patients born between January 2003-December 2005 with bilateral cleft lip and palate (BCLP), unilateral cleft lip and palate (UCLP) or cleft palate only (CPO) who had completed a 5 year speech assessment.

Methods: Data gathered for National Speech Standards were collected and analysed by cleft type (BCLP; UCLP and CPO) for resonance, airflow and cleft speech characteristics (CSCs). National outcome standards were also compared across diagnoses.

Results:

	BCLP	UCLP	CPO
Hypernasality	34%	18%	13%
Nasal emission	7%	7%	2%
Nasal turbulence	5%	6%	9%
Anterior CSCs	57%	32%	14%
Posterior CSCs	50%	21%	12%
Non-oral CSCs	41%	27%	17%
Passive CSCs	31%	22%	13%

Conclusions: BCLP shows consistently worse outcomes for speech (with the exception of airflow errors) than other cleft types. CPO shows the best outcomes. Currently all cleft types are measured against the same speech standards. The authors question whether this should continue to be the case.



Oral Abstracts

Monday 7th April 2014 – 14:53

A novel way of assessing velopharyngeal insufficiency in the paediatric cleft population

Andrew Gardner, D Wynne, C Russell, A Ray, L Crampin, L Campbell, M Devlin

Introduction: The current assessment of velopharyngeal insufficiency in the cleft population involves subjective, unpleasant or invasive methods (speech and language assessment, nasendoscopy and videofluoroscopy).

To achieve a recording in the normal range while performing spirometry the subject being examined requires a good nasopharyngeal seal. Patients with velopharyngeal insufficiency have varying degrees of insufficiency that currently cannot be quantified either in their initial assessment or after an intervention. Spirometry is a well tolerated, non-invasive, quantitative examination in the paediatric population using specialised interfaces to maximise the child's cooperation.

Methods: We carried out pre and post-op spirometry on patients undergoing velopharyngeal insufficiency surgery as a preliminary study and we will present our results.

Discussion: We are presenting the technique and preliminary results of a novel, non-invasive, quantitative and well tolerated method to assess velopharyngeal insufficiency and its response to surgery in the cleft population.

Monday 7th April 2014 – 15:01

The impact of late cleft palate repair on speech development: a retrospective analysis of 39 consecutive cases over a 20 year period

Marc Swan, N Pancewicz, D Sell, M Pinkstone, G Thorburn, P Morris, BC Sommerlad, L Kangesu

Background: Late cleft palate repair is considered to have a poor functional outcome with persistent disordered speech.

Methods: All patients aged two years or older with a delayed diagnosis of an isolated cleft palate referred to the North Thames Cleft Service from January 1994 to December 2013 were retrospectively assessed. Patients with bifid uvulae and submucous clefts were excluded.

Results: Of 39 patients, 24 were female. Sixty-nine percent were born in the UK. In 31% English was their second language. Mean age at presentation was 7.3 years (SD 8.8, median 4.0). Mean age at palatoplasty was 7.6 years (SD 8.9, median 4.1). Mean follow-up was 8.7 years (SD 6.7, median 5.5). Twenty-nine had soft palate clefts (7 complete); the hard palate was involved in 10 patients. Mean cleft uvula width was 12.8 mm (SD 7.9).

Post-operatively 75% of patients achieved normal resonance with 19% having mild hypernasality; 69% had normal articulation with 31% having non-oral cleft speech characteristics. No articulatory improvement was seen in the patient aged 42. Three families obtained medico-legal compensation.

Conclusion: Palatoplasty should be offered to all patients with a delayed diagnosis of cleft palate; with appropriate therapy the majority will achieve good articulation and normal resonance.



Oral Abstracts

Monday 7th April 2014 – 15:09

Speech Therapy and Hearing Loss: is there a link for cleft palate patients?

Sinéad Davis and Sharon Baker

Background: At the 2013 Craniofacial Conference one presenter suggested there may be no correlation between hearing status and speech in cleft patients. Seemingly at odds with our perception, we reviewed the relationship between hearing and speech development in patients in South Wales.

Method: Information was collated through review of 23 casenotes for the 2006 cohort of patients with a diagnosis of cleft palate +/- lip.

Results: 5 year records were available for 22 patients, 16 of whom received speech therapy for cleft speech characteristics (CSCs). Compared with 44% of those who required speech therapy, none of those in the 'non-therapy group' had a bilateral hearing loss at age 5 yrs. In addition, when reviewing hearing history, we identified that 77% of those who had developed posterior and non-oral CSCs requiring therapy had a positive history of hearing loss; all of whose problems started by age 2.

Conclusion: The identification of a hearing loss by the age of two is associated with, though not exclusively related to, the development of CSCs (cleft speech characteristics) and the need for therapy. If rationalising resources, undertaking audiological assessment at 2 rather than 5 years is likely to confer greater benefit on patients and services alike.

Monday 7th April 2014 – 15:17

An investigation of factors influencing speech articulation outcomes aged 5 years

Lorraine Britton

Children with a history of cleft palate frequently develop articulation difficulties requiring surgery and or speech and language therapy. The incidence of articulation difficulties forms one of the UK National Speech Outcome Standards.

To identify factors which influence articulation outcome aged 5 years a retrospective statistical analysis was undertaken on Speech Audit Recordings for 206 consecutive 5 year olds with cleft palate born in Trent from 2001-2006. Descriptive statistics and logistic regression were used to investigate whether there were any statistical differences between the children with or without significant articulation difficulties aged 5 years on a range of variables including cleft type, type and timing of surgery, history of hearing problems or history of secondary surgery for speech.

The articulation outcome aged 5 showed significant correlations with most factors investigated. However, sample sizes were smaller for some variables due to difficulties accessing the data and some of these associations may result from one variable influencing another.

Using logistic regression to control for confounding variables, three factors continued to be significant predictors of poor articulation outcomes aged 5 years. These were late completion of primary surgery, history of structural speech difficulties and cleft type, particularly BCLP.



Arnold Huddart Presentations

Monday 7th April 2014 – 16:00

Fistula incidence after primary cleft palate repair – a meta-analysis of 9,444 patients

Joseph Hardwicke, Bruce Richard

Aim: The development of an oronasal fistula after primary cleft palate repair has a wide variation reported in the literature. The aim of this review is to identify the reported oronasal fistula incidence to provide a benchmark for surgical practice.

Methods: A systematic review was undertaken to investigate the incidence of fistula. Multiple meta-analyses were performed to pool proportions of reported fistulae, in each dataset corresponding to the continent of origin of the study, type of cleft, and techniques of cleft palate repair employed.

Results: A total of 9,444 patients were included. The overall incidence of reported fistula was 8.5% (95% CI: 6.3 – 10.9). There was no significant difference in the fistula incidence corresponding to the continent of origin of each study, nor the repair technique employed. The incidence of fistula in cleft lip and palate was 17.9%, which was significantly higher ($p = 0.03$) than in cases of cleft palate alone (5.1%).

Conclusions: Palatal fistula were more likely to occur in cases of combined cleft lip and palate, compared to cleft palate alone. We would recommend the use of a well-practiced surgical repair technique and treatment schedule, and audit of outcomes against the reported fistula incidence of 6-11%.

Monday 7th April 2014 – 16:10

The emerging cleft palate syndrome associated with SATB2 mutations

Rita M Ibitoye, J Clayton-Smith, F Connell, S Lynch, H Malmgren, S McKee, SG Mehta, A Nordgren, F Stewart, M Whiteford, H Firth, D FitzPatrick, DDD Study, U Kini

Background: Chromosomal deletions encompassing 2q32q33 are associated with intellectual disability (ID), cleft palate (CP) and dysmorphism. SATB2 was identified as the CP gene at this locus. Only 3 patients with SATB2 mutations have been previously reported; two had CP and all three had ID. We report eight additional patients with SATB2 mutations associated with syndromic ID and CP.

Aims: Expansion of clinical and molecular characteristics of SATB2 mutations.

Methods: Our cohort was ascertained through exome sequencing of the first ~1100 family trios in the Deciphering Developmental Disorders (DDD) study, and exome sequencing of an index case investigated at Karolinska Hospital, Stockholm.

Results: Eight patients with novel de novo heterozygous SATB2 mutations predicted to alter the SATB2 protein were identified. Seven patients were identified through DDD and one patient identified by the Stockholm Genetics Unit. CP was present in 5/8 patients and high palate in 1/8. Developmental delay was present in 8/8 patients. 5/8 had severe ID, 2/8 moderate to severe ID and severity of ID was unknown in 1 patient. Speech delay was reported in 8/8 patients and absent speech in 5/8. Abnormal dentition was present in 4/8, friendly jovial personality in 3/8 and behavioural problems in 3/8 patients. Brain MRI or CT carried out in 3/8 patients were reported to be normal.

Conclusions: Our study expands the clinical and molecular characteristics associated with SATB2 mutation, facilitating recognition of the emerging SATB2 phenotype. It appears that SATB2 mutations may be a relatively common monogenic cause of syndromic cleft palate associated with intellectual disability.



Arnold Huddart Presentations

Monday 7th April 2014 – 16:20

A comparison of non-airway interventions required in isolated cleft palate patients with and without Robin Sequence

Jessica Steele, C Florin Villar, P Morris, G Thorburn, B Sommerlad, J Hughes, R Chorbachi, L Harding, L Cochrane, P Cunningham, J Herod, M McEvoy, S Nambiar, F Abel, L Kangesu

Introduction: The airway issues described by Pierre Robin in a group of babies with isolated cleft palate are well known. The aim was to determine the associated medical problems that distinguish babies with Robin Sequence (RS) from those with no airway issues (non-RS).

Methods: A retrospective records review was performed of 119 babies born in 2003-5 with isolated cleft palate after a 5 year follow-up. The number of procedures that each child had undergone was documented, as well as their hearing and speech status.

Results: There were 30 patients with non-syndromic RS, 7 with syndromic RS and 82 were non-RS. In the RS group 38% (n=14) were grade 1, 5% (n=2) were grade 2 and 57% (n=21) were grade 3 (Birmingham Classification). Results showed that children with RS compared with non-RS were more likely to have undergone grommet insertion (51% (n=13) V 36% (n=30)), secondary palate surgery (27% (n=10) V 5% (n=4)), and intervention for feeding (NG tube/gastrostomy) (35% (n=13) V 12% (n=10)).

Conclusion: Children with RS are more likely to have undergone episodes in hospital for feeding, hearing and speech related problems. This broader burden of care suggests that RS has a disease spectrum beyond the cleft palate.

Monday 7th April 2014 – 16:30

First results from a new Cleft Aesthetic Outcome Assessment System

Husam Bella, T Tat, Y Sinha, A Gwozdz, K Wallis, B Richard

Background: The Birmingham Institute of Paediatric Plastic Surgery (BIPPS) has developed an interactive online aesthetic outcome assessment tool for the evaluation of cleft lip surgery outcomes.

Objectives: To create a validated cleft-surgery aesthetic outcome scoring system. Development of an interactive online portal, which utilizes an assessor-based automated database solution.

Methods: Cropped AP photos (5 years post UCLP) from seventy-six patients were scored by 29 cleft-surgeons on 2 occasions using our online portal/integrated database. A 5-point Likert-scale was used and hierarchical-multinomial modelling utilised for data analysis as well as Bland-Altman plots for analysis of intra and inter-surgeon variability.

Results: Analysis of the first phase of results demonstrated weak reproducibility and repeatability but no random errors. Analysis suggests the tool to be a reliable data capture method but needs exploring as to why 29 cleft surgeons have such little agreement.

Outcome: To address this observer bias, the images were further cropped to allow scoring of the nose and lip separately and then an image including both the nose and the lip (i.e. the 3-in-1 or Tri-centric scoring system). Further development is ongoing.



Arnold Huddart Presentations

Monday 7th April 2014 – 16:40

Peer Assessment Rating (PAR) of cleft patients treated within a regional cleft centre in the United Kingdom

Claire Dunbar, G Kidner, M Cobourne

Objective: To assess the standard of orthodontic treatment for cleft patients.

Method: Patients were identified from the cleft database and those born between 1985 and 1995 were included. The PAR scores were then compared to a non-cleft group.

Results: A total of 180 cleft patients were included in the study from 8 units. The median percentage reduction in PAR in the cleft group was less than the non-cleft group at 73% and 84%, respectively. Twelve percent of the cleft group had an improvement that was regarded as 'worse or no different' compared to 3% in the non-cleft group. All cleft groups had higher pre- and post-treatment scores. Patients treated with an osteotomy had a greater reduction in PAR score at 83% compared to 71%. Cleft palate and cleft lip scores show encouraging PAR improvements at 77% and 73%, respectively. Unilateral cleft lip and palate and bilateral cleft lip and palate patients had a significantly reduced improvement in PAR at 66% and 53%, respectively.

Conclusions: This study has demonstrated that if the PAR scoring system is to be used to assess orthodontic outcomes in cleft patients, adjustments must be made. A higher proportion of cases are likely to be classed as 'worse or no different' and a lower percentage change will be expected.

Monday 7th April 2014 – 16:50

Multidisciplinary Aspects of 104 Patients with Pierre Robin Sequence Treated at the Oslo Cleft Lip and Palate Team

Charles Filip, K Billaud Feragen, E-M Andersson, N Lindberg, J Skartveit Lemvik, M Rashidi, HE Høgevold, M Matzen

Methods: One hundred and four individuals with PRS and CP were included in this retrospective study.

Results: Nineteen of 104 patients were treated with a naso- or oropharyngeal tube, CPAP and/or a tracheotomy. Thirty one of 93 nonsyndromic PRS patients have had or are having surgery for velopharyngeal insufficiency (VPI), which was significantly higher when compared to a control group of 351 CP only patients ($p=0.0040$). The mean weight percentile for newborns with PRS was 30.9. It decreased to 29.9 at the time of CP repair (mean age 13.7 months) ($p=0.78$). Hypodontia was found in 36 of 81 patients with PRS over the age of six, and was encountered in the lower arch in 30 of these. Seven of 33 boys with PRS had a diagnosis of autism spectrum disorder (ASD).

Conclusion: Nonsyndromic PRS patients had a significantly higher rate of VPI surgery than CP only patients. No growth spurt was seen in the first year of life. The prevalence of hypodontia was seven times higher than in the general Norwegian population. The high rate of ASD among boys with PRS prompts further investigation.



Arnold Huddart Presentations

Monday 7th April 2014 – 17:00

A study to evaluate the effectiveness of Pre Surgical Orthopaedics in reducing the alveolar cleft width in UCLP patients

Tom Macdonald, J Green, B Patel and N Hay

This is a case controlled study of consecutively treated complete UCLP patients under the care of the North Thames Cleft Team. Study models were taken at birth, pre-lip repair and pre-palate repair for patients with and without pre surgical orthopaedics (PSO). The aim is to compare the change in alveolar cleft width in patients with and without PSO at lip repair (3 months) and palate repair (6 months).

52 patients are included, with all surgery performed by a single surgeon using a standardised protocol (BCS). PSO was provided using an active appliance as described by DiBiase & Hunter (1983). The study casts were anonymised and the assessors (TM, JG) blinded. A digital vernier calliper was used to measure the study casts. Using the Bland-Altman method the measurements showed good repeatability and agreement. At 3 months, the PSO group showed a reduction in cleft width, however no significant differences were found between the groups at 6 months. This suggests that the repair of the lip has the greatest effect on the alveolar cleft width at 6 months.

We feel that in the absence of further longitudinal evidence to the contrary, the use of PSO is questionable.

Monday 7th April 2014 – 17:10

A retrospective study to analyse the relationship between social deprivation and 5 year speech and language outcome

James Barry, Dr Butterworth, Mr Hodgkinson

Introduction: Currently speech and language outcomes and geographical demographics are collected at five and ten year review for Cleft palate $\pm$ lip patients. However, this data does not include or analyse the impact of social deprivation. We hypothesise that there is no relationship between five year outcome and deprivation.

Method: We collected speech and language outcome data for all Cleft Palate $\pm$ lip patients between 2002 and 2007 at the Newcastle site of the Northern and Yorkshire cleft services. This data was based on outcomes 2 and 3 of the National SLT standards. All 153 datasets compiled were operated on by the same surgeon. Postcodes at time of surgery were matched to a percentage deprivation based on the English indices of Deprivation 2007. This index amalgamates multiple deprivation indicators; economic, social and housing issues into a single score for each Lower Super Output area (LSOA). Four patients were excluded having fallen outside the remit of English indices.

Results: The percentage deprivation ranged from 2.3% to 74.9%, mean value of 30.8%. Kuskall-Wallis analysis showed there was no relationship between deprivation and outcome 2; structural (p-value .285) or outcome 3; articulation (p-value .961), so we may accept the null hypothesis.



Oral Abstracts

Tuesday 8th April 2014 – 09:00

**Lecture: Craniofacial Analysis
for forensic identification and
archaeological investigation**

Professor Caroline Wilkinson
Dundee University

Tuesday 8th April 2014 – 09:45

**Lecture: Is the approach to a Cleft
Rhinoplasty any different?**

Mr Michael Cadier
Salisbury Foundation Trust



Oral Abstracts

Tuesday 8th April 2014 – 11:00

Managing the Adult Pathway in Cleft Care

Mr A Currie, Mr G Kidner, Mr S Popat

Managing adult patients brings different challenges to the adolescent and younger age groups. The Oxford adult clinic was established over 10 years ago after national cleft services were reconfigured. It combines the specialist skills of all the multidisciplinary team. This presentation will demonstrate how protocols were developed and put into clinical practice.

Tuesday 8th April 2014 – 11:40

Does cleft osteotomy improve quality of life?

K Tidbury, A Morton, TR Flood, S Stagnell, K French, J Burdett

Orthognathic surgery can be one of the key surgical aspects in the cleft care pathway for cleft lip and palate (CLP) patients.

The ultimate treatment aim is to improve the patients' quality of life (QOL), by improving function and appearance.

Objectives:

Assess the QOL outcomes following cleft osteotomy procedures.

Explore post operative complications of the surgery.

Methods: A QOL questionnaire was given to consecutive 35 cleft patients who had an osteotomy procedure between 2005 and 2013 at Salisbury District Hospital.

The questionnaire was given to patients to complete 6 months after their osteotomy procedure. This questionnaire evaluates reasons for these patients undergoing treatment. The questionnaire explores changes to social aspects of patients' lives such as confidence, and happiness with appearance. Finally the QOL questionnaire highlighted any post-operative complications experienced.

Results: These will be discussed.



Oral Abstracts

Tuesday 8th April 2014 – 11:48

Face-ism -Cultural bias in relation to facial shape

DF Campbell, EH Nichols, D Graham

Society favours certain facial shapes and beauty in general, it's important that this bias is identified to allow people to be judged fairly in day to day life and interactions with authority.

Simulations of facial disproportion were created and subjected to review to measure bias. It was shown that certain types of facial disproportion particularly those prevalent in treated cleft patients are linked in society to assumptions about aspects of poor character. The origins of this bias are discussed and a review of subjective and objective aspects of care for patients who have received treatment for facial disproportion are described.

Tuesday 8th April 2014 – 11:56

Cleft Repair in the Elderly Population – the South Wales Experience

Serryth Colbert, Helen Extence, Shirley Williams, Adrian Sugar, David Drake

Introduction/Aims – Surgical repair of cleft in the elderly population is controversial. Some surgeons report poor outcomes after surgical repair, and advise against treating this patient group. We report the outcomes of surgical repair of cleft in a series of elderly patients with unrepaired cleft lip and or palate.

Materials/Methods – We review the South Wales experience of treating elderly patients with unoperated cleft lip and or palate. We document the presence of speech impairment, behavioral problems, depression and low self esteem due to teasing about their facial appearance and ability to communicate.

Results/Statistics – Our results confirm an improvement in speech, quality of life and aesthetic outcomes after surgical repair of cleft in this series of elderly patients with unrepaired cleft lip and or palate.

Conclusions/Clinical Relevance – We advise the cleft team to consider surgical repair of the untreated cleft lip and or palate in the elderly population. Further research is needed to objectively detect the primary aesthetic needs of elderly patients with cleft lip and or palate, which along with the subjective needs defined by the patient, should determine the aim of the planned treatment interventions in this patient group.



Oral Abstracts

Tuesday 8th April 2014 –12:04

Patient and Parent Satisfaction – How to measure and report

Dr Vanessa Hammond, Consultant and Lead Clinical Psychologist

The National Cleft Psychology SIG was asked by the CFSGBI council to make some recommendations as to how patient and parent satisfaction could be measured. This presentation will summarise this process and the recommendations as well as detailing the final proposals of the CFSGBI council. A pilot study of the proposals has been undertaken and the results of this will be presented and discussed. The issues in relation to including patient and parent satisfaction in the Quality Dashboard will also be discussed.

Tuesday 8th April 2014 –12:24

Starting a family: the experience of parents with CL/P

Nicola Marie Stock and Nichola Rumsey

Background: One of the key challenges facing young adults with CL/P is decision-making around starting a family, due to the increased likelihood of their own child being diagnosed with CL/P. Should this occur, a second key challenge is how to deal with their child's diagnosis and subsequent treatment.

Aims: To explore the views, experiences and possible support needs of this unique group of parents in order to inform the services provided by non-specialist Health Professionals, cleft teams and genetic counsellors.

Methods: Telephone interviews were conducted with 24 parents with CL/P. 8 had children with CL/P, while 16 had children without CL/P.

Results: Qualitative Thematic Analysis identified five themes. Accessing accurate information and appropriate support around heritability presented a significant challenge. Parents described feelings of responsibility and distress at their child's diagnosis, as well as a number of factors which had helped or hindered their adjustment. Parents also described ways in which their own experiences had impacted on their parenting style, and how becoming a parent had changed the way they felt about their own cleft.

Conclusions: Young adults' understanding of what it means to grow up with CL/P may impact on their decision to start a family and their experiences of having children. Methods of supporting prospective parents through this potentially difficult stage will be discussed.



Oral Abstracts

Tuesday 8th April 2014 –12:32

Family Impact in Cleft Lip and Palate children in New Zealand

John M D Thompson, Megan Sanders, Harriette van de Zee, Peter V Fowler

Aims: There is a scarcity of information in New Zealand of how having a child with a Cleft Lip and/or Palate impacts on the family. We thus set out to assess quality of life (QoL) in families with a child with cleft lip and/or palate from 1 month to 18 years of age.

Methods: We randomly selected patients to receive questionnaires on quality of life using the Peds-QL family impact module.

Results: Questionnaires are currently available for 163 (41%) of the 400 sent out. The median total score was 90.3 (range 11-100) with 20% of family's reporting scores of 100 and hence no impact. The health related quality of life (HR-QoL) had a median of 93.8 (range 18-100) with 33% reporting no impact, whilst the family summary score had a median of 100 (range 9-100) with 54% reporting no impact. The scores were lowest for the worry and emotional subscales.

Conclusions: Cleft Lip and/or Palate has a wide ranging but mostly small effect on family QoL, this is more notable for HR-QoL than for family functioning. The majority of this impact on QoL appears to be due to increased worries and emotional effects

Tuesday 8th April 2014 –12:40

The Patient Voice – how to create effective patient involvement

Becky Gowers, Rosanna Preston

Aim : The National Service Specification (NSS) for England and Wales states: "Each cleft team will facilitate/encourage user involvement by including (a minimum of 2) patient representative(s) in their service development and review processes and meetings". Less than half of the cleft teams meet this specification. The aim of this project is to understand the barriers to involving patients and how they might be overcome.

Method: Discussion with a mixed group of cleft health professionals, information from a shared learning group on user involvement and feedback from patient representatives are summarised.

Results: There are a range of barriers to user involvement for both patients and health professionals. Barriers for patients include practical issues about attending meetings and knowledge and skill gaps. For health professionals they include time and other resources, confidentiality, finding the right patient, concerns about how to implement patient suggestions and communication skills.

Conclusions: Patient Involvement can improve the quality of service and is a requirement of the NSS. Training and resources are needed for patients and cleft professionals to allow the patient voice to become an effective resource for the cleft teams. This topic will be discussed in more depth at a joint workshop on Sunday 6th April.



Oral Abstracts

Tuesday 8th April 2014 – 12:48

Changing Faces Practitioners and Cleft Services- Outcomes for the first twelve months of a new NHS integrated post

Orla Duncan, Felicity Mehendale, James Partridge, Elizabeth Noble, Sam Cheatle, Carolyn Wesson

Aims/Background: Psychosocial support from Changing Faces (CF) complements multidisciplinary cleft/craniofacial services, including psychology. However, families given information about CF may hesitate to make contact by phone or online. This audit reports on a collaborative project to bring this support 'closer' by setting up the first Changing Faces Practitioner (CFP) post within the NHS.

Methods: A 0.5wte CFP based in Paediatric Psychology (managed jointly by Psychology and CF) worked with plastic surgery and cleft services from Aug2012-Aug2013. Patients (63 cleft-service, 56 other facial disfigurements) received brief-interventions in outpatients or sessions/home visits where additional support was required.
Service evaluation questionnaires-
Immediate post brief-intervention
Before/after session
≥2 months post-session by independent assistant-psychologist
Formal multidisciplinary-team feedback

Results: Service delivery models, integration with existing services, guidelines for onward referral to psychology, data sharing/compliance between NHS and CF, clinical supervision/training have been established.
Patients' frequently identified goals were-
Managing questions/comments regarding appearance
Dealing with teasing/bullying
Support with treatment decisions
Patients/parents reported brief-interventions were very helpful/helpful (98%) and sessions were very helpful/helpful (100%) in addressing these goals. All clinicians reported CFP integration improved services. The CFP post has been funded for a further 2 years.

Conclusions: Results suggest integration of a CFP into NHS pathways/services improves quality of care.

Tuesday 8th April 2014 – 14:00

Lecture: Cleft Care UK CFSGB&I – The Results

Introduction: Andy Ness, Methods: Martin Persson. Structure (Appearance and models) Tim Jones & Rana Al-Ghatam, Speech: Debbie Sell, Liz Albery & Sue Mildinhall. Psychology: Andrea Waylen. Closing remarks and discussion: Jonathan Sandy



Oral Abstracts

Tuesday 8th April 2014 – 15:00

Short Lecture: BMP-2 for Alveolar Bone Grafting in Cleft Patients

Nivaldo Alonso

Tuesday 8th April 2014 – 15:15

Use of the daVinci® Surgical Robotic System for posterior pharyngeal wall and palate surgery in the cleft patient - a feasibility study

Khurram Khan, Tom Dobbs, Tim Goodacre

Aims: Robot-assisted surgery has becoming increasingly routine replacing open and laparoscopic techniques with recent extension to uses in head and neck surgery through trans-oral access. Advantages of robot-assisted surgery include the ability to access confined spaces, enhanced dexterity instruments with intuitive movement, motion scaling, tremor elimination, and 3-D endoscopes with true depth perception. The aim of this study was to investigate the technical feasibility of trans-oral robotic surgery to access the posterior pharyngeal wall and palate for potential use in the cleft population.

Methods: A variety of positions were used with the daVinci Surgical System (Intuitive Surgical, USA) 0 and 30-degree 3D endoscopes and 8mm training instruments to determine optimal visualization and surgical access of the palate and posterior pharynx in a paediatric airway mannequin. The optimal positions were used to simulate posterior pharyngeal wall surgery. Experiments were recorded with still and video photography.

Results: Trans-oral robot assisted surgery is technically feasible in the paediatric cleft population.

Conclusions: The as yet unreported use of robotic-assisted cleft palate surgery may considerably enhance a surgeon's ability to perform difficult procedures of the palate and posterior pharynx in selected patients with limited access as well as lay the foundation for potential novel techniques.



Oral Abstracts

Tuesday 8th April 2014 – 15:23

The Cleft Collective Cohort Studies: An update

Kerry Humphries, Nicola Stock, Beate St Pourcain, Martin Persson, Yvonne Wren, Maggie Bailey, Nichola Rumsey, Jonathan Sandy

Funded by the Healing Foundation, The Cleft Collective is the world's largest cleft lip and palate research programme to date. The study will address three questions commonly posed by parents of a baby born with a cleft:

- What has caused my child's cleft?
- What are the best treatments for my child?
- Will my child be OK?

Up to 3,500 children and their families will be recruited to the Gene Bank and Birth Cohort Study. Capitalising on the centralisation of care in the UK, this research will be carried out in close collaboration with each of the UK cleft centres. Biological samples and questionnaire data will be collected.

During the Summer of 2013, a successful feasibility study was carried out in partnership with the Bristol based Cleft team at Frenchay hospital. The aim was to pilot the collection and storage of biological samples. This enabled the study to move to the next phase to work with all cleft teams and recruit families around the UK. This recruitment phase started in December 2013. Alongside this, recruitment of the 'Cleft Care UK' sample has also been implemented.

This presentation will provide a current update and what will be achieved next in this study.

Tuesday 8th April 2014 – 16:00

Superheroes

Stephanie Jalland of the Hoodwink Theatre

Tuesday 8th April 2014 – 16:10

Lecture: Towards understanding the brain mechanisms of parenting; Insights from cleft lip infants

Morten Kringelbach



Craniofacial Society of Great Britain and Ireland

Oral Abstracts

Tuesday 8th April 2014 – 16:40

Presentation of prizes

Tuesday 8th April 2014 – 16:45

Craniofacial Society Annual General Meeting



Posters

Contributing to better cleft care – improving children's social confidence through physical challenge and social interaction

Tina Owen, Julia Cadogan, Irena Morgan, Rosemarie Winter

Background: Children around ages 8-12 years develop increasing awareness of self and difference. Feeling different can affect children's confidence with their peers. This paper outlines an Activity Day run for children in years 4-7, designed to increase their sense of agency and body confidence and thereby their confidence with peers.

Intervention: 70 children took part in one of several Activity Days in 2011-2013. These were funded by the local branch of CLAPA. The children were supported in trying physical challenges including abseiling, climbing, canoeing, and circus skills. The children met others similar to themselves and team members in a non-clinical setting, facilitating a sense of belonging and breaking down barriers with clinicians.

Results: The children completed questionnaires reporting on their confidence around making new friends and speaking to other children. Pre and post results showed a significant increase in confidence in both these measures from the beginning to the end of the event. ($P < .000$)

Conclusion: Providing opportunities for achievable physical challenges alongside meeting others similar to oneself can be effective in improving children's social confidence. Because of the improvements shown, there are plans to run these events annually around the region.

The use of oramorph as post-operative analgesia following cleft lip and palate surgery

Dr Elin Jones, Dr Janet Stansfield, Dr Ursula Dickson

Background: Following the withdrawal of oral codeine from our hospital formulary we audited the effectiveness of an oramorph regime for the treatment of post-operative pain following cleft lip and/or palate surgery.

Methods: We prospectively analysed the intraoperative and postoperative (both as an in-patient and at home) analgesia requirements of thirty-eight children undergoing cleft surgery in our institution. Pain scores, time to first oral intake and parental satisfaction were recorded as measures of analgesia regime. We were also able to compare the effectiveness of oramorph to codeine from previous data collected.

Results: Our results showed that our patients were more likely to receive simple analgesia such as paracetamol and ibuprofen following the introduction of oramorph. Patients were less likely to receive oramorph than the previously used codeine. When used, oramorph at a dose of 100 mcg/kg provided effective analgesia. The time to first oral intake was approximately halved following the introduction of oramorph. We have also included results from follow up at home of those who were given oramorph on discharge.

Conclusion: Some interesting 'teething' problems with oramorph have been documented, which led to the development of a patient information leaflet on oramorph to ensure parents could use it safely and confidently.



Posters

North West, Isle of Man, North Wales (NWNW) Cleft Network Nursing Audit. Breast feeding outcomes within a defined cleft population

Lynn Douglas Clinical Nurse Specialist (CNS) Cleft Lip and Palate

UK guidelines on infant feeding recommend exclusive breast feeding for 6 months. Babies with a cleft lip can usually breast feed but cleft palate militates against direct breast feeding. Exclusive breast milk feeding is demanding but possible. Cleft clinical nurse specialists (CNS) seek to support parents' feeding choices and optimise children's health and growth in preparation for surgery. There is minimal research into breast feeding and clefts. What is best clinical practice? How well do parents achieve their wish to give breast milk to their children with a cleft? Do they feel supported?

Method: A one year prospective audit targeted 66 potential breast feeding mothers in the North West North Wales Cleft Network with a feeding questionnaire; eight weeks post delivery, auditing against local and national breastfeeding standards.

Results: Replies reported excellent compliance with cleft breastfeeding standards and positive feedback about support received. Information regarding 44 women's breastfeeding experience may help identify future research themes. A team away day is planned to re evaluate the CNS role in the light of current NHS Baby Friendly Initiative guidelines.

What is the orthodontic treatment need in patients with cleft lip and/or palate?

R Chawla, N Ullah, S Deacon

Aim: To establish the level of need for orthodontic treatment in patients with cleft lip and/or palate when assessing their malocclusion with the Index Of Treatment Need (IOTN) index.

Method: A retrospective cohort who had been assessed for orthodontic treatment at the South West Cleft Unit, Frenchay Hospital was assessed. The IOTN was assessed based on the malocclusion factors identified in the notes and on study models, excluding the 5p score for CLP, which would normally define the need for treatment as "very great" based on the cleft diagnosis alone independent of the features of the malocclusion. Other factors such as gender and cleft type were also recorded.

Results: From 67 patient records assessed 81% of patients were categorised as grade 4 or 5 on the IOTN index, indicating they had a high level of need for orthodontic treatment. The 6% which had little need for treatment had either CL or CP. Cleft type was a significant factor affecting the IOTN assessment. Gender was not a significant factor for orthodontic need.

Conclusion: A significant majority of patients diagnosed with CLP have a great need for orthodontic treatment due to malocclusion factors, such as impacted teeth or a pronounced reverse overjet, rather than from their cleft diagnosis alone.



Posters

The 6 C's and Written Cleft information for Parents and Children – A way Forward

Maureen Warren, Nichola Hudson, Jane Sibley, Tina O'Neill and Emma Waterworth

The Chief Nursing Officer's 3 year vision and strategy (Compassion in Practice¹) for nursing and midwifery includes the 6 C's framework of Care, Communication, Compassion, Commitment, Competency and Courage – the report states "these are the values that motivate us to want to work in health and care in the first place". It is only right that we identify and incorporate this framework in our work.

There are many aspects to consider when attempting to produce, informative and user friendly written information; such as client group (children are not mini adults and require information tailored to their age and perception²), relevance, readability, font size and quality of illustrations/photographs³.

This poster focuses on the written information the Spires Team produce for the children and their families from antenatal to teenage years, with emphasis how this fits into the 6 C's framework. This along with pointers for writing patient information for children and adults aims to create discussion among teams to look at the written information they have and stimulate ideas for the future. Author suggests a shared data base of patient information across all cleft centres would enable all staff to improve the quality of information produced and develop skills in writing that information.

1 Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser (2012) Compassion in Practice, Nursing Midwifery and Care Staff, Our Vision and Strategy. Crown Copyright (available from www.commissioningboard.nhs.uk)

2 Patient Information Forum (2010) Guide to producing Health Information for Children and Young People. (available from www.pifonline.org.uk).

3 Department of Health (2003) Toolkit for Producing Patient Information. Crown Copyright. (available from N.H.S. Response Line

Speech therapy for cleft speech characteristics: progress and influencing factors

Siwan Cassidy (main author) and Sara Howard (dissertation tutor for MSc in Speech and Cleft).

Background: Around 50% of children born with a cleft palate require speech therapy. Little is known about the most effective treatment approach for cleft speech errors or factors associated with slow progress in therapy. There is no collectively used outcome measure to track progress during speech therapy.

Aims: Create an outcome form to measure the success of therapy. Identify confounding factors which impact success in therapy.

Methods and Procedures: A prospective audit of progress made over a series of sessions for 27 children receiving speech therapy at a regional cleft centre. Factors thought to impact progress in therapy were identified from the literature and clinical experience. The degree of progress was analysed in light of these factors.

Outcomes and results: Most children made progress during the intervention period. Factors which correlated with good and poor progress are identified and discussed. Some of the factors have not been previously recognised in the literature.

Conclusions and Implications: This study has identified factors thought to impact progress in speech therapy which are now considered when planning and providing therapy at the regional cleft centre. A new way of measuring progress using the stages of articulation is proposed.



Posters

Speech and Language Features in children with 22q11 deletion syndrome

Sharon Baker, Speech & Language Therapist & Helen Extence, Lead Speech & Language Therapist, South Wales Cleft Team

Aim: To identify key features in speech and language development for children with 22q11 deletion syndrome.

Method: Speech and language therapy (SLT) clinical notes of 32 patients aged between 30 years and 18 months diagnosed with 22q11 deletion syndrome known to the Cleft team in South Wales were reviewed.

Results: All patients had a history of delayed onset of language as noted in the literature (Scherer et al, 1999 & Solot et al, 2001). Those who had velopharyngeal dysfunction had used glottal or pharyngeal articulation as the predominant feature of their speech prior to surgery. A high pitch or distinctive voice quality was noted in half of the patients, as was difficulty in co-ordinating the articulators. All patients who had required SLT intervention to develop speech sounds were noted to have received ongoing, weekly therapy sessions in order to make progress.

Conclusion: We have used the information to inform community SLT colleagues about 22q11 deletion syndrome in order to identify children who may not have been previously diagnosed with the condition. We are better informed to answer families' questions, have developed a MDT clinical pathway and are using the information in order to plan SLT services to this patient group.

Improving Speech Outcomes in Trent Regional Cleft Service: the role of MDT working

Lindsay Thomason, Specialist SLT, Leicestershire Partnership Trust and Lorraine Britton, Lead SLT, Trent Regional Cleft Service.

Audit is mandatory in cleft care. Making improvements to service delivery is the final stage in the audit cycle. Speech is recognised as an important outcome measure in multidisciplinary cleft care.

The results of 5 year speech audit data from 2001-2003 births indicated that Trent Regional Cleft Centre was not meeting UK National Speech Outcome Standards. In 2010 a multidisciplinary action plan was formulated with the aim of improving speech outcomes.

The plan aimed to: lower the age at primary palate surgery, improve post-operative review in order to identify and manage palatal fistulae, improve hearing management, improve early identification of the need for secondary surgery for speech, and implement an SLT early intervention programme for children aged 2-3 years.

A review in 2013 suggests that many of these changes have been successfully implemented. Early speech outcomes at age 2-3 years are positive although further changes are also being considered. Given the length of the audit loop more time is needed before the impact of these changes on 5 year speech outcomes is seen. Nevertheless national multicentre audit has enabled Trent Regional Cleft Centre to benchmark their speech outcomes and to begin to implement a multidisciplinary plan to improve practice.



Posters

Cleft Care in Cambodia 2013

Fiona Jeyes, Rebecca Knill, Priyanka Taneja

In the 2013 United Nations Development Report¹ Cambodia was ranked 138/186 countries on the 'Human Development Index'. Although the ranking is improving Cambodia remains a very poor country. Each year a huge swathe of the countryside is inundated for several months, making travel very difficult.

For the past 7 years City University, London, has enabled a group of newly qualified speech therapists to do a three month placement in Cambodia. Two of these new graduates² do their work in centres providing cleft palate care. The poster will give information about how patients receive their cleft care in three centres in the capital. It will include data about the the patients seen and their conditions, training offered to local staff and the legacy from this project.

There will be discussion of:

The challenges faced in providing input in a developing country where literacy is low and where parents are often engaged in working many hours of the day.

Some successes in training and in work with children.
How the project could progress in the future

¹http://hdr.undp.org/sites/default/files/hdr2013_en_summary.pdf

²Ms Taneja and Ms Knill in 2013

Using Motivational and Systemic Models to Enhance Behaviour Change and Decision-making around Surgery for CLP Service users

Angela Shanly, Clinical Psychologist

Effective, friendly communication between doctors and patients is known to be a key component of Patient Care. To be experienced constructively and to achieve successful outcomes, the patients' key concerns need to be specifically solicited and addressed.

Motivational approaches to behaviour change emphasize that simply giving patients advice to change and information is mostly ineffective and is not experienced positively by patients. The associated Stages of Change model describes behaviour change as a process involving contemplation, a decision, action and maintenance of change, and can be applied not just to specific behaviours, but to the process of making decisions about and engaging in medical/dental/speech/therapeutic procedures.

Adding a systemic perspective involves identifying key members of the client's family and social system, including professionals, who have views on the patient's life and behaviour. It includes them directly or indirectly in conversations about the advantages and disadvantages of change/having a procedure. Systemic perspectives also address the patient's values, culture, gender, and other key aspects of their identity and patterns of life which influence their behaviour/decision-making.

This poster will display more detailed information about the approaches described, which use psychological understanding to enhance the process of supporting medical and other professionals to talk constructively with their patients.



Posters

An investigation into the relative position of maxillary lateral incisors and alveolar clefts for patients of the Northern and Yorkshire Cleft Lip and Palate Service

C Williams, A Maas, CR Mattick

Alveolar clefts are grafted at a time to maximise the eruption potential of the adult tooth distal to the cleft. Conventional assessment is made at 7 years, with surgery at 9 years, allowing canine eruption through the graft at around 12 years. Early grafting is recommended if the lateral incisor is distal to the cleft. Anecdotally, a high number of patients (N&Y service) exhibited this.

This pilot investigation aimed to discover how frequently upper lateral incisors of normal morphology are found distal to alveolar clefts.

Methods: Patients were identified on the Newcastle site database. Inclusion criteria were:

All patients with an alveolar cleft
Aged 7y or over between 01.01.02-01.01.12
Radiographs available at Newcastle Dental Hospital

Results: 30% patients had lateral incisors of normal morphology distal to the cleft.

Conclusions and Implications for clinical Practice:

Visual assessment and recording of the cleft position relative to the deciduous lateral incisor should be made at the 5y audit on ALL patients with alveolar involvement by the orthodontist and surgeon.

The orthodontist should arrange appropriate radiographic investigation of the presence and position of the adult lateral incisor associated with the cleft site.

Is the Use of a Nasopharyngeal Airway the Most Appropriate Management of Airway Compromise in Infants With Pierre Robin Sequence?

Susan Esgate

Management of airway compromise is a priority in infants with PRS, both for survival of the infant and to facilitate feeding and growth. A number of documented interventions are in use but there is no uniform agreement as to the most appropriate management.

Five papers were selected and a critical appraisal checklist (CASP) used to elicit the evidence. The papers used retrospective reviews of infants with PRS treated within regional cleft services. Information extracted included degree of upper airway obstruction, feeding issues and airway management, including positioning, use of nasopharyngeal airway or more invasive interventions i.e. tongue-lip adhesion, tracheostomy, etc. Cohorts varied between 22 and 104, over a range of three and a half to twenty years.

Results indicated that conservative management, in the majority of infants, is the most appropriate. Most babies within the studies were managed using the least invasive techniques of positioning or by insertion of a nasopharyngeal airway. However, it must be acknowledged that there are some infants for which the conservative approach is not successful and, after failed trial with a nasopharyngeal airway, will need to progress to surgical intervention.



Posters

An audit to demonstrate parents perspective of care offered by Clinical Nurse specialists in North West England, Isle of Man & North Wales regional Cleft Network

Heather McClements, Dianne Phare

A questionnaire was sent to all parents of babies born with a cleft lip and/or palate in 2012 within the North West England, Isle of Man & North Wales Regional Cleft Network for their views on the service offered both antenatally and postnatally by the team of Clinical Nurse Specialists.

Antenatally 45 questionnaires were sent out. Of those, 19 parents returned their completed questionnaire (42% response rate). 138 questionnaires were sent out postnatally. Of those, 41 parents returned their completed questionnaire (30% response rate). 46% of post natal returns were from parents with an antenatal diagnosis and 54% were diagnosed post natal. This presentation produces the reports with both positive and negative feedback received from completed questionnaires and planned changes to care as a result of the feedback.

Clinical nurse specialists and paediatric dentists working together to improve early dental home care

S O'Connell, J Smallridge, S Butcher, S Moran
G Murphy, H Shekede, E Southby, A Young

Because of the paucity of paediatric dental services and the known greater risk of children with clefts developing dental caries we aim to deliver dental advice in many ways and from different team members. The nursing team deliver advice as per the Nursing Dental Health Standards (NDHS), families also receive written information at 5 months and 12 months from the dental team. Those associated with the hub centre attend a combined nursing, speech and dental visit at 18 months old. It is important that the advice is delivered in an easy to understand form and repeated frequently.

We looked at the number of occasions at which the CNS's delivered advice, the outcomes of whether the child had stopped using a bottle and attendance levels with the family general dental practitioner. These figures were compared with a previous audit.

CNS had delivered dental advice on between 1 and 5 different occasions, with an average of 2.8.
98% were registered with a local dentist
97% were brushing twice daily with appropriate paste
57% off bottle at 18 months review

Standards of delivering advice were being met but disappointingly there was still a high resistance to stopping the bottle at the recommended age.



Posters

Service-user evaluation of an antenatal group for parents expecting a baby with a cleft lip and/or palate

S Trenchard, C Taylor, L Halpin, J Williams, D Phare & L Douglas

Introduction: The antenatal period is an important time for adjustment to cleft diagnosis. Parents can access specialist information, advice and support from their professional team, but also from other parents who are in a similar situation. The Manchester branch of the North West North Wales and Isle of Man Cleft Lip and Palate Network have offered an antenatal group for parents expecting a baby with a cleft, with the aim of addressing their information and support needs.

Method: Evaluation forms were distributed at the end of each antenatal group between February 2012 – December 2013. All attendees (n=61) were invited to provide feedback, and 58 questionnaires were completed (95% response rate). Qualitative analysis was undertaken to generate themes from open-ended responses regarding the benefits of attending the group.

Results: 100% of attendees felt they had benefitted from the group, with 71% providing the highest possible rating. Attendees reported that meeting others and sharing experiences, meeting a baby with a cleft, and gaining reassurance were specifically beneficial. 100% of attendees felt that the group should continue to be offered to expectant parents.

Conclusion: The antenatal group is considered a helpful and relevant resource to parents expecting a child with a cleft.

Disparity of post-operative Care in Cleft Surgery

Dorothy Duncan & SIG Nursing Audit Group

To compare the difference in pre and post operative care across regional centres. Evaluate the care with regards to evidence based practice and equity of care for individuals with cleft.

Design: Information was collected from all cleft centres across the UK to identify the care given pre and post operatively. The data was compiled by the specialist nurses from each centre and collated by the nursing audit group. Information elicited the use of arm restraints, antibiotics, feeding method, pre-operative swabs and pacifier use.

Results: Data showed a wide variation in practices both inter and intra centre. The majority of centres do not use arm restraints, and many allow pacifier, or teat feeding post-operatively. There are minimal research studies/evidence to support any of these practices, rather these are based on anecdotal surgeons' preferences.

Conclusion: There appears to be no consistent approach to service delivery of pre and post operative care throughout the cleft centres, and insufficient evidence to support care delivery. There is a need for further research to identify best practice for those aspects entrenched in day to day practice. 'Ritualistic practices' must be examined for clinical and cost effectiveness.



Posters

The NOSI – an innovative prosthetic treatment option for nasal speech associated with velopharyngeal dysfunction

Ginette Phippen, Mark Richards & Paul Grew

The NOSI is an innovative but simple prosthetic device that is placed in the nostrils to prevent nasal escape of air. The device has been developed in partnership with maxillofacial technicians at Salisbury Foundation NHS Trust and put forward for further development as a Trust innovation.

The NOSI is made from soft silicone and custom made to fit each patient, although a range of 'off the shelf' sizes is also being developed. The prosthesis contains a valve mechanism that allows the patient to breathe air in through the nose but prevents air escaping through the nose during speech. This results in a slightly hyponasal vocal resonance (quality of voice) which is generally considered to be more acceptable, less effortful and easier for others to understand.

The NOSI is suitable for patients with nasal speech where surgery is contraindicated or declined and who may be considering the option of a palatal prosthesis. Both children and adults may benefit from this approach.

Preliminary evaluation with four patients is currently underway at SFT, including assessment of acceptability as well as the effect on speech. This poster will outline the development and evaluation of the device and plans for future research.

A rare case of Parry-Romberg syndrome

Timothy McSwiney, Mary McKnight

Aims: A case of Parry-Romberg syndrome is presented. This is a rare neurocutaneous syndrome characterised by progressive atrophy of the tissues beneath the skin, most commonly affecting one side of the face. It is also known as progressive hemifacial atrophy.

Method: An 8 year old female presented to the craniofacial unit with flattening of the left infra-orbital rim and zygomatic prominence, asymmetry of the maxilla and atrophy of the soft tissues affecting the lip and left side of the face. There was associated hypodontia of the upper lateral incisors and a cleft like alveolar defect. A definitive diagnosis of Parry-Romberg syndrome was based on clinical examination and radiographic investigation.

Results: The patient underwent initial Coleman fat-grafting to the left brow and cheek to improve soft tissue contour. Once growth was complete, definitive orthognathic treatment was completed, consisting of a bimaxillary osteotomy and downfracture of the left maxilla and an iliac crest bone graft.

Conclusion: The precise aetiology and pathophysiology of Parry-Romberg syndrome remains unknown. Medical management can involve the use of immunosuppressive drugs whilst surgical management may involve a combination of autologous fat transfer, flap/pedicle grafts, orthognathic surgery and bone grafts once the condition appears to have burned out.



Posters

Developing an Integrated pathway of care for children having an Alveolar Bone Graft and their families

Dr Jane Lewendon, Maureen Warren, Stephen Robinson, Tim Flood, Anne-Marie Parker, Sarah Diment

Between the age of 7 and 11 yrs, children with an alveolar cleft require a bone-graft (ABG) to ensure their permanent dentition erupts normally. This can be the first surgery of which the young person is fully aware and anecdotally, parents often report their own anxiety when faced with preparing their child for this operation. In Spires, we had existing speciality-specific pathways for ABG. However, feedback from patients and clinicians indicated that an integrated pathway, mapping the family's own journey through this process would enable the team to better coordinate their input with each family and ensure that every patient and their family receive appropriate, timely and individualised care within a clearly defined and measurable pathway. The process of developing the pathway and suggestions for evaluation and future directions are outlined.

Major cleft surgery experience for a trainee in a short trip abroad

Diaa Othman, Chris Hill, Mohammad Riaz

Overseas Plastic Surgery Appeal (OPSA) is a UK-based charity that has been sponsoring biannual plastic surgery camps in Pakistan for 15 years. UK-based plastics and cleft lip & palate surgeons, trainees, nurses and anaesthetists have been attending these camps to provide reconstructive procedures, including cleft lip & palate and nose repairs.

Under Mr. Riaz's guidance, a cleft unit has been opened, providing a state-of-the-art service based on UK guidelines. The new hospital is fully equipped with outpatient clinics, speech recording and assessment, photography, dental and orthodontic treatment and audiometry. Within few months a paediatric unit with ICU and maternity facilities will be opened.

Cleft Hospital Gujrat is a 24/7 hospital. The teams from abroad play an essential role in teaching and training and performing specialist procedures. In November 2013, over six days 87 cases were performed, of which two thirds were clefts. Two theatres running simultaneously allow trainees to maximise their learning opportunities.

Such surgical exposure in countries that do not have the NHS privilege is invaluable to UK trainees. The social experience is particularly extraordinary. This facility which started as charitable services to local community is now recognised nationally in Pakistan, with the aim to match international care level in the near future.



Posters

**Complications of Ventilation Tube Insertion:
A Nested Case Control Comparison of Cleft
and Non-Cleft Children**

I Smillie, S Robertson, A Yule, DM Wynne & CJH Russell

Background: Optimising hearing in cleft palate patients by early management of otitis media with effusion (OME) is essential for speech development. Past evidence suggested higher complications from ventilation tube (VT) insertion in cleft palate patients leading to a trend not to treat these patients surgically. However, past studies failed to match comparison groups for age and gender.

Methods: 60 cleft palate patients had VT insertion between May 2002 and October 2012 at the Royal Hospital for Sick Children Glasgow. A non-cleft control group, matched for age and gender, was selected from a database of 2943 VT insertions.

Results: There was no statistically significant difference in otorrhoea rates ($p=0.522$). However, the non-cleft cohort had 151 documented cases compared to 121 in the study group (ratio 1.25:1). Other reported complications were also higher in non-cleft patients with totals of 43 and 25 respectively (ratio 1.7:1). There was no difference in ENT attendance for complications ($p=0.659$).

**Distraction and alveolar arch management
with the 'Magdeburg Distractor' in a male
young child with a complete bilateral lip
and palate cleft.**

Dr Tarek Stanarius and Dr Christian Zahl

Introduction: In patients with complete bilateral clefts, the widening of a collapsed alveolar arch and the management of a prominent premaxilla could confront the surgeon and the orthodontist with complex difficulties.

Aim: Here we present the surgical procedures and our treatment protocol for a male 4 years old foster child with alcohol embryopathy and complete bilateral cleft who profited from the 'Magdeburg Distractor' due to a collapsed maxilla and prominent premaxilla.

Therapy: We started expanding the alveolar arch with the 10mm 'Magdeburg-Distractor' in a first step. After 4 weeks, the distractor was changed to the larger 15mm version and we started the retraction of the premaxilla after the estimated width had been reached. Therefore, wires and elastics were applied to the premaxilla.

Results: We achieved within a short time a stable alveolar arch, integrated the premaxilla and could stabilize the palatal configuration for further treatment.

Conclusion: The 'Magdeburg-Distractor' is a useful device to manage bilateral cleft associated difficulties under a multistep protocol in young children with complex disorders. It offers an uncomplicated, verifiable and reliable strategy to widen the collapsed maxilla and to integrate the prominent premaxilla into the alveolar arch at the same time.



Posters

Validation of 3D printer models of alveolar clefts produced from CBCT scans

C Kasaven, GT McIntyre, PA Mossey

Objective: To determine the accuracy of 3D printer models of alveolar defects produced from cone-beam computed tomography (CBCT) scans.

Participants: CBCT images for 15 consecutive subjects with UCLP were analysed.

Methods: The volumes of the alveolar defects from the i-CAT CBCT scans (Imaging Sciences International, Hatfield, Pennsylvania, USA) were calculated: 1) Computational analysis of the 2D CBCT slices using a) MATLAB (Mathworks, Inc., 2009, Natwik, Massachusetts) and b) Volume Graphics Studio Max 2.2 (VGSM) (Volume Graphics, 2012, Heidelberg, Germany). 2) Virtual 3D CAD models were created using Mimics (Materialise, Leuven, Belgium), 3D printed and micro-CT scanned with the volumes calculated using VGSM. Significant differences between volumes were identified using the Friedman Test ($P < 0.05$) using SPSS Statistics 19.0 (IBM Corporation, New York). Three observers identified the superior and inferior slices of the cleft defects for all 15 subjects and an Intraclass Correlation Coefficient (ICC) was used to assess inter-observer reproducibility.

Results: Interobserver reproducibility was almost perfect ($ICC = 0.987$). Although the volume of 3D CAD models of alveolar defects produced from CBCT scans was consistently over estimated in comparison to both computational analysis methods, this was not statistically significant ($P = 0.074$).

Conclusion: The volume of 3D printer models of alveolar defects produced from CBCT scans was over estimated.

Surgical management of otitis media with effusion in children with cleft lip and/or palate born in England between 1997 and 2005

Kate J Fitzsimons, Lynn P Copley, Jan H van der Meulen, Channa Panagamuwa, Scott A Deacon

Objective: To assess grommet insertion practice among pre-school age children with cleft lip and palate in England.

Design: Analysis of national administrative data of hospital admissions (HES).

Setting: National Health Service hospitals.

Patients: Patients born alive between 1997 and 2005 who underwent surgical cleft repair.

Results: 8,269 children were included. Before the age of five, 3,015 (36.5%) children received grommets. Of these, 33.2% received their first grommets at the same time as their primary cleft repair and 33.3% underwent multiple grommet insertion procedures. The most common age for the first procedure was six to 12 months. Children with a cleft affecting the palate were more likely to receive grommets than children with a cleft lip alone (45.5% vs. 4.5%). Grommet insertion practice also varied according to year of birth, absence or presence of additional anomalies, socio-economic deprivation and region of residence.

Conclusion: Grommets practice appears to vary according to the clinical characteristics of the patient. The observed differences in practice according to deprivation and region of residence suggest differences in practice and access to this type of procedure.



Posters

Does either deprivation or age have an effect on the surgical outcome of alveolar bone grafts in patients with cleft lip and palate?

J Robinson, S Deacon, P Revington

Aim: To determine whether deprivation or age of a patient at the time of surgery has an effect on the radiographic outcome of alveolar bone graft operations performed during 2004 – 2013.

Method: Using 331 consecutive patients who had alveolar bone grafts, Index of Multiple Deprivation (IMD) scores and rankings were determined using post codes. Age was recorded at the time of the operation. These were compared to prospective Kindelan scores of the bone grafting procedure from radiographs at a 6 month review.

Results: Sufficient data was available for 302 of 331 consecutive patients (91.2%). IMD rankings distributed into Quintile 1 (13.6%), 2(18.9%), 3(23.5%), 4(20.9%), and 5(23.2%). 276 of 302 (91.4%) procedures were assessed to be a success (Kindelan score 1, 2). Logistic regression analysis showed no statistical evidence between the success of a patient's bone grafting procedure and IMD score ($p=0.571$) or deprivation national ranking ($p=0.351$). Ages ranged from 7 to 53 (median 9 years). Statistical analysis showed significance between age at the time of surgery and Kindelan score.

Conclusions: There is no evidence for a relationship between deprivation scores and radiographic success of bone grafting procedure in the South West. The age of the patient is a significant factor.

An Evaluation of Alveolar Bone Grafting: A Survey of UK & Ireland Cleft Lip and Palate Teams

P Jauhar, T Macdonald, B Patel and N Hay

Alveolar bone grafting of the maxillary cleft site prior to the eruption of the permanent canine, is an established procedure. This stabilises the maxilla, provides bony support for the erupting permanent dentition and facilitates orthodontic tooth movement. In 2005 there was a national survey conducted in America amongst cleft teams analysing their alveolar bone grafting protocols. Their results highlight inconsistencies in care. The current literature appears to lack a recent survey on the existing protocols of cleft teams in the UK & Ireland with regards to alveolar bone grafting for cleft patients. Therefore, an online survey, consisting of 24 questions was sent out to all Orthodontic & Surgical members of the cleft teams in the UK & Ireland.

The aim of this project was to determine the main factors influencing the timing on alveolar bone grafting, to assess the types of radiographs used to evaluate bone grafting sites pre- and post-operatively and the views of the profession on the need for expansion prior to grafting.

Our hypothesis is that there is good agreement amongst the regional cleft centers in the UK & Ireland as to the timing of alveolar bone grafting, the type of radiographs being used and whether or not expansion is required preoperatively.



Posters

The Importance of Wine Tasting in Cleft Surgery

R Seselgyte, L Kangesu, P Morris, M Swan, G Thorburn

Introduction. Several antiseptic agents are available for preparation before palate repair. We therefore arranged an unusual 'wine tasting' of antiseptic agents, normal saline and sterile water to assess the taste.

Methods. Thirty one volunteers were enrolled in the study and were asked to evaluate the smell and taste of chlorhexidine gluconate 0.05 % (Unisept, Sterets®), chlorhexidine gluconate 0.015% with cetrimide 0.15% (Tisept, Sterets®), 0.9% sodium chloride and sterile water. The smell and taste were evaluated applying a 5 degree scale, with tasting notes.

Results. Unisept and Tisept had a surprisingly unpleasant aftertaste and sensation in the mouth. This could persist for hours, but was improved by rinsing with water. Significant differences were noted in taste between all solutions ($p < 0.01$) except comparing Unisept vs. 0.9 % sodium chloride ($p = 0.71$). Unisept had significantly better smell than the other solutions ($p < 0.01$).

Conclusions. Antiseptic agents used for oral cavity preparation before palate repair have an unpleasant and persistent aftertaste that may add to the difficulties of getting these babies to feed in the postoperative period. We recommend washing with water afterwards.

Internal 3D landmarking: A novel approach to assess 3D skeletal changes following orthognathic surgery.

A Almkhatar; B Khambay; X lu; J McDonald; A Al-hiyali; N Jabar, T Goto; A Ayoub

Introduction: Modern three-dimensional (3D) imaging techniques has made it possible to measure the 3D skeletal changes following orthognathic surgery. This study aimed to validate a novel method for assessing the 3D jaw position following orthognathic surgery.

Methods: A total of nineteen known surgical jaws movements were simulated and measured manually on a plastic skull. After each simulation a CBCT scan was taken and superimposed on the cranial base of the un-operated skull scan using voxel-based registration. Eight anatomical landmarks were placed directly on the DICOM-slices and their distance to a common frame of reference were obtained. Inter-and intra-examiner reproducibility were assessed. A paired t-test and interclass correlation test were performed.

Results: There was a high level of agreement between the manual and digital readings in the three dimensions, with a mean difference of 0.25 ± 0.18 mm. A high intra- and inter-examiner reproducibility for the 8 landmarks was observed. Landmarks error distances were 0.35 ± 0.17 mm and 0.3 ± 0.15 mm for inter- and intra-examiner tests respectively. No statistically significant difference was detected ($p < 0.05$), in addition to a high agreement between the readings.

Conclusions: This novel method is valid and has an acceptable level of accuracy to assess the 3D positional change of maxillo-mandibular complex following orthognathic surgery.



Posters

Development of an Aesthetic Outcome Tool for Complete Unilateral Cleft Lip and Palate: Comparison of Consultant Panel Assessment and the Computer Based Program 'SymNose'

Katy L Wallis, Christopher Wearn, Husam Bella, Alexandra Freeman, Bruce Richard

Aim: To compare the subjective assessment of aesthetic outcome following repair of complete UCLP by a panel of Cleft Consultants with a quantitative computerized symmetry system (SymNose).

Method: Cleft consultants throughout the United Kingdom were invited to score 75 cropped anteroposterior photographs of the nasolabial region of 5 year olds with surgical repairs of complete UCLP on a 5-point scale. This was repeated 1 month later. The photographs were also processed using SymNose, a computer based program, which calculates the degree of asymmetry for the nose and upper lip.

Results: Twenty-five Cleft Consultants completed the scoring survey on 2 occasions. Comparing the Consultant Panel ratings with the SymNose assessment, the overall agreement was poor with low correlation. The panel agreement was greater with the SymNose lip outcome measure (correlation of 0.24) than with the nose outcome measure (correlation of 0.09).

Conclusion: There was poor correlation between the panel scores and the quantitative scores of symmetry generated by SymNose. Symmetry is only one aspect of what is subjectively assessed in photographs. The greater correlation with lip symmetry suggests features are weighted differently by the assessors and further research is needed in this area.

A study of patients with Van der Woude Syndrome within the North Thames Cleft Network

Kate Parker, James Green, Norman Hay, Brijesh Patel

Aim: To analyse the epidemiology and dental features of patients with Van der Woude Syndrome across the North Thames network.

Method: Data was collected retrospectively from medical records, radiographs and study models for all Van der Woude patients across the North Thames network.

Results: The cohort included 65 patients. 52.3% were male with an age range of 1 year 10 months to 38 years 6 months. The most common associated clefts were cleft lip and palate (40.0%: 24.6% bilateral, 15.4% unilateral), isolated cleft palate (36.9%), sub-mucous cleft palate (7.7%) and cleft lip and alveolus (6.14%: 3.07% bilateral, 3.07% unilateral). Five families had more than one child with Van der Woude syndrome with clefting presentations differing between siblings. Dental analysis was performed on 24 patients. 87.5% had missing teeth, most commonly upper lateral incisors (55.1%) and upper second pre-molars (18.4%). Mesio-distal widths were commonly narrower than normal range. The clefting presentations and dental abnormalities were more common in these Van der Woude patients than the general cleft population.

Conclusion: This study presents the largest dataset of Van der Woude patients in the UK and adds important information to the current understanding of its epidemiology and its clefting and dental presentations.



Posters

Patient and parent satisfaction with cleft multidisciplinary clinics at Great Ormond Street Hospital

Kate Parker, Charlotte Larner, Emma Piepenstock, Norman Hay

Aim: To assess patient and parent satisfaction with cleft multidisciplinary clinics.

Method: A validated anonymous questionnaire was given to all parents and patients eight years and over following cleft multidisciplinary clinics. Ten areas were assessed using a 4 point Likert scale as well as open comments. Data has currently been collected for one month; by the time of the conference data will have been collected for three months.

Results: 47 questionnaires have been completed by parents and 11 by patients (return rate: 87.04%, 91.67%). Average patient age 4.56 years (range: 11days – 20years). 53.19% were White British with 70.21% having English as their first language. High rates of satisfaction were reported by patients and parents. Over 91% of parents answered 'certainly true' in all categories and 100% of patients answered 'certainly true' in 6 categories. No parents or patients answered 'not true' or 'unsure' in any category. Response rates and satisfaction have improved since the previous questionnaire in 2012. Highlighted for improvement were waiting times and easing transition into adult care.

Conclusion: There is a high level of parent and patient satisfaction with cleft multidisciplinary clinics. Areas for improvement have been highlighted and will be targeted to further improve the service.

Management of Otitis Media in Pierre Robin Sequence And Impact on Long Term Hearing

Heide Mills, Raouf Chorbachi, Hassan Sohawon, Lesley Cochrane, Loshan Kangesu

Pierre Robin sequence is a triad of micrognathia, glossoptosis and airway obstruction accompanied by a wide, U shaped, cleft palate. OME is recognized sequelae of cleft palate due to Eustachian tube dysfunction and failure of middle ear ventilation.

PRS patients are consequently prone to OME and chronic suppurative otitis media. The associated hearing impairment adversely affects speech development and language acquisition. Patients frequently require multiple grommet insertions with the risk of associated complications.

Following review of 64 patients with PRS who were part of the Cleft Protocol at Great Ormond Street Hospital, a separate otological care pathway is advised. We advocate full ABR assessment due to the observed higher occurrence of sensorineural hearing loss, with selective use of grommets and the option of using hearing aids as the first line audiological management.



Posters

Longitudinal assessment of the changes in dental arch relationship in patients with an isolated cleft palate between the ages of 5 and 10.

S Shah, J Green, B Patel, N Hay

Aim: The aim of this study is to evaluate the need for collecting audit study models at 5 and 10 years for patients with an isolated cleft palate (ICP).

Design: Retrospective longitudinal study.

Method: As part of the audit protocol for the North Thames Cleft Service, dental records were collected on 60 consecutive ICP patients at 5 and 10 years of age. The 5 year index and 10 year GOSLON yardstick were used to analyse these models. The models were scored by trained and calibrated researchers (SS, NH & BP) and the rankings were repeated one week later. The 5 year and 10 year indices scores were compared for each patient to determine changes in the growth and dental arch relationship over this period.

Results: All models were ranked in groups 1, excellent (5 year index 83% and 10 year 87%) or 2, good (5 year index 17% and 10 year 13%) 5% moved from 1 to 2 and 5 % moved from 2 to 1.

Conclusion: Given the apparent minimal effect on growth and occlusal relationships at 5 years and the minimal effect longitudinally at 10 years the team no longer collect audit models in ICP patients.

Assessment of velopharyngeal closure using MRI in patients.

M Pinkstone, D Sell, M Wylezinska-Arridge, M Birch , AD Scott, ME Miquel

Introduction: Assessment of velopharyngeal closure is performed clinically to guide and evaluate cleft palate repair surgery using x-ray videofluoroscopy or nasendoscopy. Recent advances in real-time MRI could allow speech examination and provide extra-anatomical information without use of radiation.

Methods: Work was carried on a 1.5T clinical scanner on 20 healthy adult volunteers and in 13 patients (7-57 years). Imaging included anatomical scans and real-time speech assessment (10 frames.s⁻¹) in views similar to videofluoroscopy and nasendoscopy, and during extended phonation ("ah", "ee"). Standard clinical speech tasks were used. Sound was recorded using a fibre-optic microphone and speech movies created off-line. The data was evaluated using our standard clinical protocol.

Discussion: The developed protocol was successfully applied to 11 patients. In 2 subjects data was not acquired due to excessive artefacts caused by orthodontics devices. With real-time sequences it was possible for speech therapist to carry out a speech examination during imaging and obtain speech movies. Anatomy of interest, including the levator veli palatini could be visualised from the proton-density scans.

Conclusion: A comprehensive MRI protocol, including speech assessment, was developed and successfully applied to cleft patients. Further data acquisition and analysis is under way to finalise its translation into clinical practice.



Posters

Effects of orthodontic appliances on quality of cleft and speech MRI.

M Wylezinska-Arridge, M Pinkstone, N Hay, MJ Birch, ME Miquel

Aims: With MRI playing an increasing role in Cleft palate management, it becomes crucial to assess the effects of commonly used orthodontic appliances on the quality of both anatomical images and speech MRI.

Methods: A variety of commonly used orthodontic appliances were studied on 1.5T scanner using Turbo Spin Echo and Balanced Steady State Free Precession sequences previously applied in morphological and real-time speech imaging. Images were evaluated for the presence and size of the artefacts.

Results: Metallic orthodontic appliances have different effects on MR image quality in this clinical simulation investigation. The most extensive artefacts are associated with the presence of stainless steel arch wires, brackets and stainless steel molar bands. With those appliances the diagnostic quality of soft palate images will be most likely severely degraded, or unusable. All non-metallic or Ni/Ti or Ni/Cr alloys appliances are of little concern.

Conclusions: Many appliances result in severe artefacts, particularly those manufactured from stainless steel, which may degrade image quality. It is recommended that removable appliances, especially those containing stainless steel are removed prior to imaging. The compatibility of fixed orthodontic appliances with magnetic field should be considered in cleft palate patients that may require MRI.

Outcomes of secondary alveolar bone grafting in the West Midlands: A retrospective review.

L Dunphy, N Uppal, A Rennie, I Sharp

Objective: The aim of this study was to determine the quality of secondary alveolar bone grafting following an iliac crest bone graft harvest or guided bone regeneration (Bio-Oss, Stimulan) and to assess postoperative donor site morbidity using an open (trapdoor flap) technique.

Design: A retrospective review of alveolar bone grafts performed from 2007-2013 at the Queen Elizabeth Hospital, Birmingham by one surgeon using an open technique. Alveolar bone graft results were assessed using pre and post operative occlusal radiographs. The sample was scored by a panel of trained assessors, following a calibration exercise, using a modified Kindelan index, with weighted kappa statistics for intra-observer and inter-observer reproducibility. A total of 79 patients, 59 unilateral and 20 bilateral alveolar clefts underwent an operation. Of these, 64 underwent alveolar bone grafting with cancellous iliac bone and the remainder underwent Bio-Oss (12) and Stimulan (3) augmentation. Variables potentially influencing outcome were evaluated including graft type, cleft type and severity, age at grafting and complications.

Results: The mean length of hospital stay was one night. Donor site complications included temporary neuropraxia of the lateral cutaneous nerve of the thigh (1) and an abnormal gait (1). Recipient site complications included wound dehiscence (4) and infection (1).

Conclusion: Although the management of the alveolar cleft remains controversial, secondary alveolar bone grafting is the most widely accepted approach and the results of our review indicate that it is a well tolerated procedure with minimal morbidity reported.



Posters

An investigation of the use of a modified wax bite as an alternative to dental impressions in recording occlusal relationships in 5 year olds.

Hammond J, Davies M & McNeil A

Aim: Study models have been used for several decades to audit the jaw relationship and growth of cleft patients. The taking of the impressions, used to construct such records, are an unpleasant experience for many of our young patients. In contrast the taking of a wax bite, used to articulate, the models is well tolerated.

This study was undertaken to see if a modified wax bite could be used to record sufficient definition of the labial and buccal surfaces of the dentition to act as an alternative to study models.

Method: 5 year old Cleft patients attending for audit underwent 1) Huddart Bodenham score of their occlusion on clinical examination, 2) had a 'modified wax bite' taken, from which a single model was prepared, N=14.

Subsequently the constructed models were score using the Huddart Bodenham method and compared with those from clinical examination, taken earlier, to assess agreement using a weighted Kappa tests.

Results: The weighted Kappa statistic for the deciduous 55, 54, 53, 51, 61, 62, 63, 64 & 65 were 1.00, 0.98, 0.96, 0.90, 0.92, 0.98, 0.93 and 1.00 respectively suggesting very good agreement.

Conclusion: The level of information captured and the ease and simplicity of the taking the bite suggest a large study should be considered.

Is Segmental Le Fort 1 Tooth-Borne Distraction an alternative option?

R Pabla, M Pinkstone, N Gohil, P Ayliffe, B Patel

Correction of craniofacial deformity from maxillary hypoplasia often requires combined orthodontic/maxillofacial surgical management.

Maxillary surgery is conventionally Le Fort 1 advancement +/- vertical positional change. A significant potential complication is velopharyngeal incompetence and consequent speech deterioration. To minimise this in patients at risk of or already suffering with speech impairment, segmental maxillary osteotomy and distraction is a little practiced, alternative surgical option.

Limited application of segmental maxillary distraction means there is little data regarding outcomes. A novel aspect to our approach is tooth-borne distraction as opposed to bone-borne distraction.

Aim: To assess speech and surgical outcomes.

Method: Retrospective record review.

Results: 10 patients were treated using this technique. 9 were treated between 2008-2011 and 1 in 2003.

Dental injury occurred in 3 patients. There were 2 wound infections.

2 patients required further maxillary osteotomy and distraction. Another patient underwent subsequent formal Le Fort 1 advancement.

Speech was unaffected in 7 patients. 2 patients suffered speech deterioration. A Hynes pharyngoplasty resolved moderate hypernasality in one of these patients.

Data was unavailable for 1 patient.

Conclusions: Segmental maxillary osteotomy is associated with surgical risk. In conjunction with tooth-borne distraction, it does protect speech in most patients who would otherwise be at risk.



Posters

5 Year Olds' Index Outcomes for Patients with Unilateral Cleft Lip and Palate (UCLP) born 2000-2007

Joyce I Russell, Nikki E Attack

Introduction/Background: The 1998 Clinical Standards Advisory Group (CSAG) report demonstrated poorer maxillary growth for 5-year-olds with UCLP born 1989-91 than in Scandinavian centres. This study audits UCLP maxillary growth of children born during and since subsequent reorganisation.

Material and Methods: Since 2007, study models for 5-year-olds with UCLP have been independently assessed annually, using the 5 Year Olds' Index (Attack et al 1997). Grouped results have been compared with CSAG outcomes using Chi-Squared Tests.

Results: There has been a gradual increase in numbers of annual records, although including dental photographic records, reaching 160 assessed in 2014, for those born 2007. For the third consecutive year, all UK centres participated. For those born 2000 – 2007, records of 1007 patients with UCLP, from at least 1358 known (for whom records could be expected) were assessed (74% inclusion rate). Outcomes were 44% excellent/good (1/2); 31% fair (3); 25% poor/very poor (4/5). Scores for those born 2007 were: excellent/good 47%; fair 34%; poor/very poor 19%.

Conclusion: Annual results show some variation. Over all, both the patients born in 2007 alone and in the eight years 2000 - 2007 show better maxillary growth compared with CSAG ($p < 0.001$).

How does it heal? Images of a vomerine flap, daily photograph for 5 weeks

Mohammad Nassimizadeh, Sinha Yashashwi, Hussam Bella, Bruce Richard

Introduction: While animal histological studies have suggested both scar tissue formation and wound contraction play important roles in palatal cleft repair healing (Leenstra 1997), little is known on the mechanism of mucosalisation of exposed vomer and raw surface of the vomerine flap following elevation of the mucoperiosteum for primary closure of the hard palate.

Aim: To observe the mucosalisation following elevation of a vomerine flap.

Method: This is an observational, prospective, single case study. Photographs were taken daily of the roof of the mouth for 15 days and then at weekly intervals for a further 3 weeks, using a 120 degree endoscope.

Results: Healing appears to occur in 4 phases. Day 1-9 slough and clot was seen over the wound, making visualisation difficult. Day 10 pink islands were seen below the slough and palatal mucosalisation began from the palatal edge. Day 10-14 the depth of the base of the flap appeared to advance towards the oral surface. Day 18 mucosalisation of the vomer was seen alongside bridging to the palatal side.

Conclusion: While little is known of the mechanism of healing, post palate repair, our study is the first to provide a visual record and establish a timeline of the process.



Posters

Prospective Study: Botulinum Toxin Intervention for Drooling

Bilal Gani Taib/Casey Vaughan, Htin Maung, Kelvin Ung, Paul Nixon, Ravi Sharma

Aims: To ascertain the efficacy and duration of effect of Botulinum-A toxin injections in drooling children.

Method: A prospective study was carried out on drooling patients at Alder Hey Children's Hospital. A series of questionnaires both before and after the treatment were provided to the patient's carers. This allowed quantitative analyses to be made for the efficacy of the Botulinum injections.

Results: The mean age of the cohort ($n = 33$) is 10.0 years old. 23.9% of the children have a form of epilepsy and 19.6% are cerebral palsy patients. The therapeutic window for the first treatment is on average 8.5 weeks. With subsequent injections the therapeutic window increases to 14.0 weeks and 22.0 weeks respectively. Using the Wilcoxon signed rank test the mean drooling severity and frequency is significantly reduced ($P < 0.05$) at both 1 month and subsequent appointments, which are on average 6.6 months apart. Similarly the visual analogue scale was found to be significantly reduced over the longer follow up period ($P < 0.05$). Service satisfaction was 99.7%.

Conclusion: The efficacy of Botulinum toxin treatment is exemplified by significant reductions in the frequency and severity of drooling. Combined with a great service satisfaction it remains a viable treatment option.

Is there evidence for impaired growth in children with unilateral cleft lip and/or cleft palate?

Beate St Pourcain, Martin Persson, Rosemary Power, Andrew Wills, Jonathan Sandy, Andy Ness

Some research has indicated that children with cleft, including isolated forms, experience growth limitations during the first stages of their development. Within this study we investigated whether five-year old children with non-syndromic unilateral CL/P ($N=258$, CleftCareUK, born 2005/07) show impaired growth in comparison with typically developing children with respect to weight, height and head circumference.

Anthropometric measures were transformed into sex- and age-adjusted standard-deviations scores (SDS) and compared against UK/European reference populations as well as 8365 children from a UK-population-based birth cohort (ALSPAC, born 1990/91).

CleftCareUK children were on average smaller (Height-SDS = $-0.11(0.99)$) and lighter (Weight-SDS = $-0.04(1.08)$) compared with ALSPAC children (Height-SDS = $0.21(0.99)$; Weight-SDS = $0.21(1.02)$, $P < 0.001$), but not against the 1990 British growth reference ($P > 0.068$). It is possible that growth acceleration counterbalanced the effect of cleft-related growth delay, as we observed larger height and weight measurements in ALSPAC children compared to the same standard ($P < 0.001$).

There was also a trend for larger head circumference in CleftCareUK compared to ALSPAC children ($0.002 < P \leq 0.74$), depending on the selected reference population used for score transformation, though a direct comparison of scores against each reference provided mixed results ($-0.44 < \text{SDS} \leq 0.58$).

Our findings suggest that the selection of reference is crucial for the interpretation of growth-related parameters in children with cleft.



Posters

Secondary alveolar bone grafting in children with bilateral cleft lip and palate. A report of the outcomes of 44 consecutive patients treated using a surgical technique involving premaxillary osteotomy

Rupert Scott, Sami Stagnell, Tim Flood

Background

Patients with cleft lip and palate usually undergo secondary alveolar bone grafting in the mixed dentition phase to restore dental arch form, facilitate eruption of teeth, close oro-nasal fistulae and restore bony anatomy. Access to close fistulae without premaxillary osteotomy is difficult, with 10% of patients having symptomatic fistulae post-operatively with other techniques. A technique of bilateral alveolar bone grafting involving premaxillary osteotomy is described with its results in a cohort of 44 consecutive patients.

Methods

All bilateral cleft lip and palate (BCLP) patients undergoing surgery between 2000 and 2013 in a single specialist cleft unit were retrospectively identified. Medical records and radiographs were used to assess surgical outcomes. Patients were followed up for a minimum of six months.

Results

44 patients underwent bilateral alveolar bone grafting with premaxillary osteotomy in the period studied. Bone grafting was highly successful and no premaxillae were devitalised. Fistula recurrence was 9%. All were asymptomatic.

Conclusion

This surgical technique of secondary alveolar bone grafting using a premaxillary osteotomy gives superior access to close oro-nasal fistulae compared to other techniques. It restores the dental arch form and facilitates eruption of teeth into the cleft. It is safe and does not devitalize the premaxilla.

Technological Advances in Cleft Imaging

Ambika Chadh, Geoff Charles-Edwards, Trevor Coward, Piet Haers, Mark McGurk

This presentation outlines the evolution in cleft imaging research that is currently underway at Kings College London/South Thames Cleft Centre. Post-natal imaging protocols for cleft patients lack standardization and depend on available facilities with pre-operative imaging still heavily reliant on the limited information derived from ionizing radiation-dependent modalities such as x-rays and CBCT / CT scans. Additionally, assessment of aesthetic outcomes postoperatively can involve cumbersome stereophotogrammetric set-ups.

Through the collective efforts of image scientists, medical engineers and clinicians, however, advances in image technology hold promise to significantly improve our understanding of the cleft defect whilst further accommodating the paediatric patient. Specific advances discussed include the transition from 2D to 3D to 4D imaging, the move towards non-invasive, non-ionising radiation modalities such as high resolution intraoral US and diffusion MRI, the portability of existing imaging methods such as stereophotogrammetry and – perhaps most challengingly – the potential to co-register different imaging modalities to give unprecedented information on surface and underlying tissues together.

Whilst some developments are in their infancy they represent the future of bedside cleft imaging with the potential to deepen our understanding of the defect, continually and objectively assess interventions and facilitate future therapeutic options such as stem cell therapies.



Posters

Morphology of the soft palate in volunteers and repaired cleft palate patients using MRI

M J Birch, M Pinkstone, C Theopold , AD Scott, M Wylezinska-Arridge, ME Miquel

A detailed understanding of the soft palate and associated musculature, and in particular the Levator Veli Palatini (LVP) is desirable in the management of Cleft Palate patient. With its high soft tissue contrast and lack of ionising radiation, MRI could play a vital role.

Methods: High resolution MRI protocols were optimised for soft palate contrast and LVP visualisation. Twenty healthy volunteers and thirteen patients (7-57 years) were scanned on a 1.5T Philips Achieva. The optimum contrast was obtained using proton density weighting. A multi-slice high-resolution (0.6×0.6×1.2mm³, 0.6mm overlapping slices, 0.6mm isotropic reconstructed, TE=12ms, TR=3000ms) turbo-spin-echo acquisition was acquired. Image quality was assessed and LVP measurements used by the surgical cleft team performed by 2 independent observers.

Discussion: Imaging successful in all volunteers and 11 patients, in 2 artefacts due to orthodontics were too extensive to carry-out the protocol. Both inter and intra-observer variability were good and measurements in agreement with the literature. Image quality was lower in some patients due to motion (young patients) and/or orthodontics.

Conclusion: The use of MRI in cleft palate management is at a very early stage. This study has demonstrated optimal MRI parameters for LVP measurements and provided valuable morphological information.



Craniofacial Society of Great Britain and Ireland

Special Interest Group Agendas Wednesday 9th April Sloane Robinson Building, Keble College

The Royal College of Speech and Language Therapists Special Interest Group The O'Reilly Theatre

09:45	Registration
10:00	Welcome and AGM
10:45	Ipad survey. Siwan Cassidy
11:00	Tea/Coffee
12:15	Operation Ouch. Jayne O'Connell
12:30	Lunch
13:30	Being understood: speakers, listeners and the negotiation of speech intelligibility in context. Professor Sara Howard
14:30	Faces of Hope: Hola Guatemala! Beth Fitzpatrick
15:00	Case presentations 1) Neurofibromatosis (NF1). Julie Davies 2) Fitting the pieces together - language, speech and palate function in a toddler with 22q11 DS. Nicole Prenderville
16:00	Close

Paediatric Dentistry Special Interest Group Seminar Room 1

09:30	Welcome and presentation of 2007 5yr national dmft data: Jeanette Mooney
10:00	DMFT/dmft Calibration training sessions update: Jackie Smallridge CLEFT
10:15	Coffee
10:45	Update re: CDG/CRG: Jackie Smallridge Review of data collection forms/Quality Dashboard/CRANE/National Service Specification requirements: Jeanette Mooney/Jackie Smallridge
11:00	CLEFT CARE 11: Analysis of oral health data/projects: Jackie Smallridge
11:30	Realistic Dental Partnership Support in Developing Countries for Cleft Lip and Palate Patients: Dr Ian Robertson, Director of Oak Tree Trust and Mohammed Aslam MBE, Director Midlands International Aid Trust
12:30	Lunch
13:30	Development of paediatric dentistry national care pathways
14:30	CFSGB&I Paediatric Dentistry SIG website: discussion of content

14:45	Coffee
15:15	Future presentations: CFSGB&I conference 2015 & IAPD 2015
15:45	AOB Date of next meeting: November 2014
16:00	Close

Orthodontic Specialist Interest Group Seminar Room 2

09:30	Registration
10:00	Business Meeting 1. Apologies 2. Minutes of the last meeting 3. Matters arising 4. Audit Projects 5. Education & Training 6. Research 7. New appointments 8. AOB 9. Date & Time of Next Meeting
11:00	Coffee
11:15	5 and 10 yr outcomes – Susannah Dominguez Gonzales/Joyce Russell/ Alan Gowans/Toby Gillgrass
11:45	ABG pathway – Lars Enocson Findings of National ABG Survey - Preeti Jauhar
12:15	Training (Job Spec, FTTAs & Curriculum) – Norman Hay WBA & Post CCST training pathways
12:30	Lunch
13:30	Orthognathic Surgery – Jeremy Knox
13:50	Study Models 5-20 yrs – Scott Deacon
14:10	PAR – Claire Dunbar
14:30	Cases Discussion
15:00	Tea
15:15	Update from: Cleft Development Group – Stephen Robinson CRANE – Scott Deacon TOPS Healing Foundation projects – Kevin O'Brien
15:45	AOB
16:00	Close



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Surgical Special Interest Group John Radcliffe Hospital, Education Centre

09:00	Live surgery demonstration by M Cadier & T Goodacre
12:30	Lunch
13:30	Business meeting Research Training Mortality & morbidity
16:00	Close

Nursing Special Interest Group Seminar Room 5

09:00	Annual General Meeting
10:30	Coffee
11:00	Delayed diagnosis of cleft palate Cathy Marsh
11:15	Delayed diagnosis of cleft palate – working party Alex Habel
12:00	Video Interaction Guidance Helen Gibson
12:30	Lunch
13:30	Liaison with Public Health Nurses in Eire Jane Gunn
14:00	Update on Cleft Collective Kerry Humphries
14:30	Results of Patient Satisfaction Questionnaire Heather McClements
15:00	Breastfeeding audit Lynn Douglas
15:30	Discussion/Evaluation
16:00	Close

Psychology Special Interest Group Seminar Room 3

10:00	Updates including CRG, satisfaction, KPI and Standard 38
10:30	SIG projects updates including CLAPA link MDT clinics Audit
11:00	Coffee
11:15	SIG projects update Screening guidelines
11:30	Tiers of Involvement Measure (TIM) discussion
12:30	Lunch

13:30

Guest Speaker – Helen Gibson
Video Interaction Guidance - to focus on parent-child interactions, play, feeding and maybe touch on some social skills work currently being used with young people with Aspergers

15:00

Tea

15:15

Cleft Collective update
Update on outcome measurement for psychological therapy

16:00

Close

Manager/Co-ordinator Special Interest Group Seminar Room 4

09:30	Welcome and Introductions
09:45	Terms of Reference – agreed and signed off (circulated prior to the meeting)
10:00	Biannual SIG meetings
10:15	Coffee
10:45	Commissioning Specialised Cleft Services: An overview of the new commissioning structures and how you can get involved. Michele Davis, Programme of Care Lead for the Cleft Lip and Palate CRG, NHS England
11:15	What works well in your team/ what could we do better? Each centre presents (5-10 mins) – 'The good, the bad and the ugly'! eg, Have you made improvements within the team/internal processes? What doesn't work well? Sharing of thoughts on service improvements/ how processes are done across the centres.
12:30	Lunch
13:30	Data collection – 'What, Where and How' Each Centre presents (15 mins) on their data collection methods – eg, How many pieces of paper does it take to register a new baby? How many places do we record the same data? How many other databases do the clinical staff record information?
14:45	Tea
15:15	Continuation of presentations on data collection
16:00	Close



Craniofacial Society of Great Britain and Ireland

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2014:	Mr Stephen Robinson
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1. Details taken from the website of the CFSGBI – for which acknowledgement and thanks are given



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ARNOLD HUDDART MEDAL WINNERS 1990-2013²

- | | |
|---|--|
| <p>2013 Radical Muscle Dissection In Cleft Palate Repair – What About The Lesser Palatine Nerves?
<i>Jeremy Mortimer, Felicity Mehendale and Simon Parson</i></p> <p>2012 Two potential novel loci for orofacial clefting identified on Array CGH
<i>Rita Ibitoye, Usha Kini, Joanna Roberts</i></p> <p>2011 The 5-year old index: Determining the optimal media for rating dental arch relationships in unilateral cleft lip and palate.
<i>Ourvinder Chawla, Scott Deacon, Nikki Atack, Anthony Ireland, Jonathan Sandy</i></p> <p>2010 Surgical management of the spectrum of submucous cleft palate (SMCP): Speech outcome following anatomical muscle dissection. repair of the palate.
<i>Mr Ali M Ghanem with O Gilleard, D Sell, M Birch and BC Sommerlad</i></p> <p>2009 Effect of Buccinator Mucomuscular Flaps on Speech in Cleft Palate Patients
<i>Ms Arwa Meki and members of the cleft team at Addenbrookes Hospital, Cambridge</i></p> <p>2008 Pre and perioperative Dexamethasone improves postoperative recovery following cleft palate surgery
<i>Matthew Potter, Specialist Registrar in Plastic Surgery, Radcliffe Hospital Oxford</i></p> <p>2007 The effect of presurgical orthopaedics on archform in unilateral cleft lip and palate
<i>Nadali, and MMars, A Petrie, JNoar, B Sommerlad</i></p> <p>2006 Intra Operative Blood Loss – Anaesthetic Type and Adrenaline Concentration
<i>Patrick Gillespie, Specialist Registrar in Plastic Surgery, Addenbrookes Hospital, Cambridge</i></p> <p>2005 Dimensional Stereophotogrammetry
<i>Mark Devlin, Cleft Surgery Fellow, South Thames Cleft Unit, Guy's Hospital</i></p> <p>2004 Effects of the Fgfr2 Crouzon-type Mutation on Palatal Shelf Development
<i>Chad Perlyn, Dept of Human Anatomy & Genetics, University of Oxford</i></p> | <p>2003 Assessment of Early Dental and Facial Deformity in Repaired Unilateral Cleft Lip and Palate
<i>Dr A Garrahy, Glasgow Dental Hospital</i></p> <p>2002 Sequelae of Otitis Media with Effusion among Children with Cleft Lip and/or Cleft Palate
<i>Patrick Sheahan MB AFRCSI, Specialist Registrar in Otolaryngology, Dublin, Ireland</i></p> <p>2001 Can maxillary growth be predicted from 3-dimensional parameters of neonatal study models in patients with unilateral Cleft Lip and Palate?
<i>Ms Felicity V Mehendale, Cleft Fellow in Plastic Surgery at Great Ormond Street Hospital for Children, London and St Andrew's Centre for Plastic Surgery, Broomfield Hospital, Essex</i></p> <p>2000 The Tendons of the Levator Veli Palatini
<i>Ms Felicity V Mehendale, Cleft Fellow in Plastic Surgery at Great Ormond Street Hospital for Children, London and St Andrew's Centre for Plastic Surgery, Broomfield Hospital, Essex</i></p> <p>1999 The Orthodontist's contribution to the management of Obstructive sleep Apnoea
<i>Mr A Johal, Senior Registrar in Orthodontics at the Royal London Hospital</i></p> <p>1998 Reorganisation of Cleft services - implications of non cleft anomalies
<i>Ms Lucinda Huskisson, Senior Registrar in Paediatric Surgery at The Children's Hospital, Birmingham</i></p> <p>1997 Craniofacial abnormalities in Nicosia, Cyprus, and the significance of parental consanguinity
<i>Ms Sonia Vartoukian, Dental undergraduate at King's College Dental Institute, London</i></p> <p>1996 A twenty year follow-up assessment of nasal symmetry in patients with unilateral complete Cleft Lip and Palate
<i>Norma Timoney, Senior House Officer in the Department of Plastic & Reconstructive Surgery Royal Devon & Exeter Hospital</i></p> |
|---|--|

² Details taken from the website of the CFSGBI – for which acknowledgement and thanks are given



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- 1995 Does the McComb primary cleft nose correction affect nasal growth? A longitudinal study
Mr Brian Coghlan, Senior Registrar in Plastic Surgery in the Yorkshire region
An audit of bilateral alveolar bone grafting at Great Ormond Street Hospital 1983-1993
Dr Yilin Jia, Honorary Registrar in Orthodontics at The Hospital for Sick Children, Great Ormond Street, London
- 1994 Management of 100 cases of phoneme specific nasality - a two centre audit
Mrs Liz Albery, Speech & Language Therapist at Frenchay Hospital, Bristol
Mrs Kim Harland, Speech & Language Therapist at St Andrew's Hospital, Billericay
- 1993 Growing up with a Cleft
Ms Eileen Bradbury, Clinical Counsellor in Plastic Surgery at Withington Hospital, Manchester and Lecturer at the University of Manchester
- 1992 The vascular basis of posterior pharyngeal flaps
Mr Nigel SG Mercer, Consultant Plastic Surgeon with Frenchay Healthcare Trust, Bristol
- 1991 The characteristics of pre-speech vocalisations in Cleft Palate children
Mrs Jane Russell, Principal Speech Therapist at Birmingham Children's Hospital Prepared in conjunction with Professor Pamela Grunwell
- 1990 The relationship between Intracranial pressure and restricted skull volume in children with Craniosynostosis
Mr Gault, Senior Registrar in Plastic Surgery at The Hospital for Sick Children, Great Ormond Street, London Prepared in conjunction with B Jones, D Marchac and D Renier



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Craniofacial Society of Great Britain and Ireland

A FINAL WORD FROM THE PRESIDENT

I wish you all a safe journey home and hope you were suitably inspired and informed by the conference. Thank you for taking part and we hope to see you all again next year in London. My special thanks go to all those people listed below who have helped put this conference together.

Steven Berry *Service Co-ordinator*
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Michael Cadier *Consultant Plastic Surgeon*
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