Pioneering new National Facial Oral and Oculoplastic Research Centre (NFORC) Combined media launch and public information event Wednesday 26th Nov

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PATIENTS AND SURGEONS ARE AVAILABLE FOR INTERVIEW

Sections:

1. What NFORC is and how it will improve patient treatment

2. Launch Event programme

1. What NFORC is and how it will improve patient treatment

1.This groundbreaking new research centre is a World first.

2.NFORC design and methods are revolutionary and research on its huge datasets will improve treatment for all patients suffering head, neck and facial injuries, diseases and growth disorders worldwide.

3.It is a partnership between UK surgeons and patients leading the world and defining best treatment now and researching better treatment in the future through "patient power".

4.Professor Iain Hutchison (NFORC Director) says "This is the first time all the surgeons in one nation - the UK - have combined with their patients to collect the exact details of the treatment given by each surgeon and every patient's report on the physical, social and emotional outcome of their treatment. That's how we'll work out which of the many treatments available for each condition works best".

5.NFORC has only been made possible by a unique collaboration between 3 national surgical organisations dealing with the face [The British Association of Oral and Maxillofacial Surgeons (BAOMS); The British Oculoplastic Surgical society (BOPSS) and the British Orthodontic Society (BOS) – see Facts section for more details]; and the charity "Saving Faces-The Facial Surgery Research Foundation"(savingfaces.co.uk) who are organizing the launch and funding NFORC.

6.The umbrella organization covering all the specialties treating UK Head and Neck cancer patients [The British association of Head and Neck Oncologists (BAHNO) – see Facts section] have also entered into partnership with Saving Faces and NFORC.

7.Iain Hutchison says that "Surgeons around the world are excited about this pioneering centre and want to partner us as they have nothing like it in their own country".

8."I've already had enquiries from researchers in Europe and the USA about the possibility of analyzing these huge datasets - some of the researchers have described NFORC data as a gold mine". "We've had to set up a Research Board of scientific experts to evaluate these bids from researchers". "NFORC research will eliminate the uncertainty that bedevils decision-making by surgeons who always want to improve treatment for their patients".

9.This type of research is called "clinical research" because it is conducted with patients.

10.NFORC clinical research will be allied to psychological research to improve sociological and emotional outcomes of the surgical treatment

11.NFORC research will be allied to innovative laboratory research to find those genetic markers that can predict cancer and to see how we can grow body parts as replacements for tissue loss from shotgun and blast injuries and after cancer removal.

Related Sectors:

Health :: Medical & Pharmaceutical ::

Related Keywords:

Facial :: Disease :: Cancer :: Disfigurement :: Injury :: Research :: Patient :: Pioneering :: Stem Cells :: Transplant :: Mouth :: Trauma :: National :: Health :: Treatment ::

Scan Me:

12.NFORC has been selected by The Royal College of Surgeons of England as the UK's Head and Neck Surgical Trials Unit.

13.NFORC is a national organization based at Barts and The London Medical School

2. Launch Event programme:

1.The actor Alan Rickman and The deputy chief medical officer for the NHS Mike Bewick will open the event which will be compered by Channel 4 anchor Jon Snow;

2.The French surgeons who did the first face transplant will describe how they did it and what they have learnt researching the outcomes of their surgery;

3.World-leading scientists will talk about growing / making body parts to replace the face;

4.Patients will give first-hand experience of the impact of facial injury, jaw joint problems, disfiguring facial growth disorders, mouth cancer, and melanoma on their and their family's lives.

5.Surgeons will talk about their research to improve treatment for all facial conditions and how to tailor treatment to individual patients.

6.The world-renowned Saving Faces art project will be exhibited in the foyer of the Purcell Room and Queen Elizabeth Hall.

7.There will be inter-active displays of 3D printing and other research in the foyer throughout the afternoon. **Pioneering new National Facial Oral and Oculoplastic Research Centre (NFORC)**

The Next section is a much longer 'Notes to Editors'

Bios of patients and Facial Diseases and Injuries

Face Facts

Bios of Surgeons

Clinical research facts

Saving Faces' Achievements

Bios of patients and Diseases and Injuries

1.Facial Injury

In the UK there are over 750,000 facial injuries every year and 125,000 of these are categorised as serious. They often leave permanent disfiguring scars.

Patients:

George B – is an avid amateur cyclist whose lower jaw, lip and chin were sliced off his face and lost on the road when he crashed into a solid object at speed. His face jaws and teeth were reconstructed with shoulder blade and skin from his back.

Tom H – had his nose bitten off. He had several operations using his forehead to reconstruct this.

They will describe the horror experienced by themselves and their families when injured and the long road to recovery

2.Mouth Cancer

Is the 6th commonest cancer worldwide. There are 9,000 new patients a year who develop this cancer in the UK and the incidence is rising. If other sites in the voice-box and sinuses are included there are 16,000 new patients a year. It can be the most socially disabling cancer adversely affecting speech, eating and appearance. It is twice as common as cervical cancer and testicular cancer.

Patients:

Raymond R – had a small mouth cancer 6 years ago. He participated in the 1st ever surgical research study on mouth cancer in the UK which was half funded by Cancer Research UK and Saving Faces. He had the cancer removed from the mouth and all the glands on one side of his neck to prevent the cancer's spread.

Maureen M – had her small mouth cancer removed 3 years ago in the same research study but did not have the neck glands removed.

They can talk about participating in clinical research as well as their experience of mouth cancer and the anxiety provoked by its treatment.

3.Pre cancerous conditions in the mouth

About 100,000 patients in the UK are living with pre cancerous lesions in their mouths. Some people's mouths are completely lined by these precancerous changes in their mouth lining. Most of these will never turn into cancer but none of our current tests tell us which ones will and which ones won't.

Patients:

David W – The whole lining of his mouth is precancerous. It's not possible to remove all this without causing immense harm. He has had 3 separate cancers over the last 10 years all requiring surgery. His brother never had pre cancer but developed mouth cancer about 7 years ago and despite major surgery, chemotherapy and radiotherapy he died within 3 years.

Sharon L – Sharon is a young woman who had a pre cancerous area in her mouth for several years. When she was pregnant with her third child this turned into cancer.

They will talk about the anxiety caused by the variability and uncertainty about the management of the "time-bomb" in their mouths.

4.Children with blood vessel tumours

These tumours are disfiguring and dangerous because blows to skin may cause catastrophic bleeding. They start as small red spots when the child is born and rapidly grow to enormous size within 18 months. The psychological effect on the child and their parents is disastrous because surgical removal is also fraught with danger.

Patients:

Jaia B age 9 months – Jaia had a swelling on the top of her nose that went into her right eye socket and interfered with her vision. It grew to a large size and was continuing to grow when she was treated at nine months. At their local hospital the parents had been told that there was no need for treatment as the swelling would go down with time***.***

Annie W age 9 months - Annie had a large tumour sticking out from and occupying most of her right forehead. Her mother is a surgeon who had researched the various treatments for these tumours and with some anxiety decided on surgery rather than lesser treatments. She will explain the reasons for her choice.

Jaia and Annie's parents will describe the impact of these tumours on their child's behavior, and the behavior of other children and adults.

5.Children's cuts

These are very common and usually cause immense distress to the parents. The parents not unreasonably want treatment which is painless and not disruptive to their lives with a permanent result of the least visible scar. But these wishes often conflict because in order to suture calmly and carefully the child should be anaesthetized and still, whilst the best stitch materials might require a second general anaesthestic for removal several days later.

Patients:

Clio K - *will describe her experience seeing her brother "bleeding to death" as she thought in the school playground***.**

6.Corrective jaw surgery

People with jaw and facial disproportion are frequently perceived by their peers and teachers during their formative teenage years to be less friendly, more violent and less intelligent simply based on their facial appearance. These attitudes that the patients receive blight their lives and their career prospects. Corrective jaw surgery returns their face to normal proportions and allows them to lead normal and fulfilled lives.

***Patients*:**

Sue ME - had a normal cheerful disposition but people always assumed that she was miserable because her lower jaw jutted forward and made her lower lip curl downwards in what appeared to be a grimace. Corrective jaw surgery transformed her life.

Graham

Sue and Graham will describe their experience prior to surgery and the transformation in their lives brought about by surgery.

7.Jaw joint problems

These are very common. In some countries 70% of people have reported symptoms such as clicking locking and pain from their jaw joints at some point in their lives. The management of these problems is incredibly variable and some patients go on to develop debilitating effects despite treatment.

***Patients*:**

Christine Y - *her jaw joint pains started when she was 26 and she have a variety of treatments such as mouth guards, painkillers, steroid injections before she finally had surgery on her jaw joints. Her original symptoms were of severe pain and marked limitation of mouth opening*

8.Making body parts

Patients:

Ade A - *He was a bank manager in Nigeria who had his lower jaw,*

Lower lip, chin, tongue and all his upper teeth shot off during a robbery. He underwent three operations to generate a new face.

9.Melanoma of the eye

This is a potentially lethal disease that can spread all over the body. Treatment often involves removal of the affected eye or eyelids.

***Patient*:**

Josh S - his melanoma spread from the eye down into his cheekbone, upper jaw and facial skin. All these were removed surgically and reconstructed. He will describe is experience of the disease and its treatment.

10.Radiosensitivity and bad genes

11.Stem cells and cancer

12.Cleft lip and palate

Face Facts:

1.Our Faces are the most complex part of our bodies reflecting the Face's importance to our survival and success.

2.We take in food and oxygen through our mouths to provide essential energy to keep the brain (and the rest of the body) working.

3.The bones of our face and head protect the brain from physical harm.

4.We receive messages to protect us from danger through our special senses in the face – sight, smell, taste and hearing.

5.We communicate our feelings through facial expression which helps us achieve sociological success.

6.Our social lives are built around speech and communal eating – all carried out through the mouth.

7.Finally our facial appearance can lead one of two polar opposites, acceptance or rejection.

8.Surgery is an essential part of treatment for all facial diseases like cancer, facial injuries and disorders of facial growth like cleft lip and palate. It can restore the lives of people who have cancer or facial injury. It can transform the lives of those with facial growth disorders which have led to disfigurement.

Speaker Bios:

Jon Snow

Jon Snow is a multi-award winning journalist and the longest-running presenter of Channel 4 News. He recently celebrated his 25th anniversary at the news desk, though he famously refuses to stay there, often reporting from the front lines in war-torn countries and disaster zones. He has been involved with Saving Faces, the charity which funds NFORC, since its inception. 'I work in a medium in which the face is a vital element. That's why I feel an affinity with the work of Saving Faces.'

Prof Parveen Kumar CBE

Parveen Kumar is the co-author of the world-renowned textbook – "Kumar and Clark's Clinical Medicine". Professor Kumar has served as Vice President of the Royal College of Physicians, President of the British Medical Association and President of the Royal Society of Medicine. She is Professor of Medicine and Education at Barts and the London School of Medicine and Dentistry, and Honorary Consultant Physician and Gastroenterologist at both Barts and Homerton Hospitals. She has held roles with the National Institute of Clinical Excellence and the Medicines Commission UK. She was awarded CBE for her services to medicine in 2001.

Prof Iain Hutchison

Iain Hutchison is Consultant Oral and Maxillofacial Surgeon at St Bartholomews and The London Hospitals. He is Chief Executive of Saving Faces – The Facial Surgery Research Foundation and Director of the National Facial, Oral and Oculoplastic Research Centre (NFORC).

David Verity

David Verity is a Consultant Oculoplastic Surgeon at Moorfields Eye Hospital, London. He is Treasurer of the British Oculoplastic Surgery Society and Editor-in Chief of the international journal ORBIT.

Simon Holmes

Simon Holmes is lead Facial Trauma surgeon at Barts Health and Clinical Director of Head and Neck Surgery. He has an international reputation for excellence in primary and revision facial trauma surgery. He is a trustee of the charity Saving Faces. He has authored several book chapters in the field of Facial Trauma Surgery.

Prof Piet Haers

Piet Haers is The President of the International Association of Oral and Maxillofacial Surgeons (IAOMS). He specialises in cleft lip and palate surgery and is Clinical Director of the South-Thames Cleft Team at Guys Hospital in London. He has been appointed to the National Clinical Reference Group for the commissioning of cleft lip and plate services. He is a Visiting Professor at the Postgraduate Medical School of the University of Surrey and Consultant Oral and Maxillofacial Surgeon at the Royal Surrey County Hospital in Guildford.

Prof Sue Cunningham

Susan Cunningham is a Professor in Orthodontics at UCL Eastman Dental Institute. Professor Cunningham's main research interests are in the field corrective jaw surgery for individuals with severe dentofacial deformity and patient-centred research on the outcomes of this surgery. She is currently Programme Director for the postgraduate programme in Orthodontics, one of the largest Orthodontic

programmes in Europe.

Kathy Fan

Kathy Fan is a Consultant Oral and Maxillofacial Surgeon at Kings College Hospital and a Senior Lecturer at Kings College, London (KCL). She specialises in facial deformity surgery. Her PhD was in Photodynamic Therapy at University College, London.

Andrew Sidebottom

Andrew Sidebottom is a consultant in oral and maxillofacial surgery at Nottingham University Hospitals. His specialist interest is in the management of Temporomandibular joint - TMJ (jaw joint) disorders. He is one of only 8 UK surgeons carrying out TMJ replacement. He is secretary of the British Association of TMJ Surgeons and has recently stood down as President of the European Association of TMJ Surgery. He is the invited specialist adviser for TMJ Replacement for NICE. He has published over 50 articles and 3 book chapters.

Prof Ania Korszun

Ania Korszun is Professor of Psychiatry and Education at Barts and The London School of Medicine and Dentistry, Queen Mary University of London. Her research focuses on mood disorders and particularly on the interface of depression and stress with other medical conditions. She is currently working in collaboration with colleagues from surgery and oncology on predictors of psychological wellbeing in cancer and trauma patients. Professor Korszun is the Academic Lead for Psychiatry Education at Barts, and Chair of the Education Forum at the Royal College of Psychiatrists.

Andrew Dawood

Andrew Dawood is an international expert in the field of implants and 3D printing. He has patented many innovations which are now in general use. He is in constant demand to lecture in the UK and abroad, and to treat foreign heads of state. He devotes time to Research and Development in Implant Dentistry, 3D Imaging, and 3D Manufacturing. He has honorary appointments at University College, St Bartholomew's, and The Royal London Hospitals, where he is involved in advanced implant treatments for patients requiring facial reconstruction.

Prof Lucy di Silvio

Lucy Di Silvio is President of the United Kingdom Society of Biomaterials (UKSB). She is Professor in Tissue Engineering (Biomaterials, Biomimetics & Biophotonics Group) at Guys, Kings and St. Thomas Schools of Medicine & Dentistry. Her research activity focuses on the development of stem cell technology and its application to tissue engineering solutions for bone regeneration for craniofacial and orthopaedic applications. She has published over 100 papers in peer-reviewed journals in this field, numerous book chapters and is Editor of "Cell materials Interactions".

Prof Bernard Devauchelle

Bernard Devauchelle is the pioneer of facial transplant surgery performing the first one in the world on 27th November 2005 at his University Hospital in Amiens (Picardy, France). He has been President of the European Association of Cranio-maxillofacial surgeons and the French oral and maxillofacial surgeons. He is member of the French Academy of Surgery and has been awarded honorary Fellowship of the Royal College of Surgeons of England. His courses on reconstructive surgery have trained many of the world's current leading surgeons. He is the author of more than a hundred papers. He is involved in many research projects in experimental surgery, tissue engineering, imaging and new technologies and he is the founder and director of the Facing Faces Institute (devoted to disfigured people).

Mike Fardy

Mike Fardy specialises in orofacial cancer removal and reconstruction at the University Hospital of Wales and Dental School in Cardiff. He set up the first Orofacial Oncology Service there. He has been elected President of the British Association of Head and Neck Oncologists, the specialist organisation for head and neck cancer treatment, from 2015 to 2017. Prior to this Mike was along time council member and then served as its annual conference organizer for 7 years.

Andrew Lyons

Andrew Lyons is an Oral and Maxillofacial Surgeon at Guy's and St Thoma' Hospital NHS Trust. He

specializes in dentoalveolar in head and neck cancer surgery and reconstruction. Mr Lyons has authored 3 chapters in the new Textbook of Operative Maxillofacial Surgery. He is a senior examiner in the intercollegiate FRCS and is past President of The Oral and Maxillofacial surgical section of the Royal Society of medicine. Andrews major research interest is in the adverse impact of radiotherapy to patients normal facial tissues.

Prof Ian Mackenzie

Ian Mackenzie is Professor of Stem Cell Science at the Centre for Cutaneous Research at Barts and The London School of Medicine and Dentistry. During his PhD he developed an interest in the cellular mechanisms maintaining skin and oral mucosa growth. This led him to pioneer research into the role that stem cells play in cancer. This was at a time when nobody believed that there was such a thing as a cancer stem cell. He has played a major part, through his research, of identifying stem cells in the cancer cell population and persuading the world that cancer stem cells exist and that these are the cells that must be destroyed if the cancer is to be cured. His research led to appointments directing research institutes at the Universities of Iowa and Texas in the USA before he was lured back to the UK as Vice Dean for Research at the University of Wales School of Medicine and Dentistry in Cardiff.

Ian Martin

Ian Martin has held many leadership roles in surgery in the UK and internationally. He is Director of the National confidential enquiry into patient outcome and death (NCEPOD), medical director of Sunderland Royal hospital, President of the European Association of Cranio-maxillofacial surgeons and President of the Federation of Surgical Specialty Associations (this federation is led by the president of every surgical specialty organisation in the United Kingdom and its president is elected to serve all these surgical specialties by this illustrious group of surgical presidents). He served as chair of the British Association of oral maxillofacial surgeons until 2013 and has been elected as its President for 2018.

Muy Tek-Teh

Dr Teh is a Senior Lecturer in Head & Neck Cancer Research at Barts and The London School of Medicine and Dentistry. His research focuses on the cell and molecular mechanisms of cancer development in the mouth. He has been working on a molecular cancer diagnostic laboratory test which could predict precancer to cancer transformation and the behavior of different patients' cancers. His research has featured on the BBC and in national and international newspapers.

Debators

Prof Jim McCaul

Prof Ian MacKenzie

Clinical Research Facts:

There are several things the public don't understand about surgical treatment and this is why we need to do "clinical" research:

1.They think there is a standard way of treating any condition, e.g. hip replacement.

2.But, as with all diseases or injuries there are several ways of treating the same facial disorder.

3.All of these treatments are relatively successful but of course some will be better than others, or work better on different people (e.g. different ages, sexes), or require much more complex treatment with more risks for the patient to achieve better results.

4.We don't have answers to which treatment works best in all situations and we need to do clinical research with patients to compare the different treatments and answer these vitally important questions.

5.This involves collecting accurate, relevant data on many patients' treatment and their assessment regarding the results (outcomes) of the treatment. But, like many successful studies before, such as those discovering the link between smoking and cancer, it is essential to follow up large numbers of patients after treatment, sometimes for many years.

6.The best way to collect accurate data is to use experts who understand the treatment given (surgeons) and the outcomes of that treatment (patients) to enter the data.

7.Therefore the first step in this process requires every UK surgeon to accurately record data on the treatment given to all their patients who have suffered mouth and face diseases or injuries. The second step involves patients entering their information about the physical and emotional outcome of the treatment.

8.All of this requires extra effort by surgeons and patients but fortunately all surgeons and most patients have signed up to this in preparatory studies.

9.No health service in the world has accurate data on the treatment given to patients and the outcome of that treatment. It needs data entry on the treatment by the experts who delivered it (the surgeons) and long-term follow up of the patients to find the outcome of the treatment.

Saving Faces' Achievements

Founded in 2000 by Professor Iain Hutchison to fund and lead United Kingdom research to improve the prevention and treatment of facial deformity, facial trauma and facial and mouth cancer.

In the last twelve years Saving Faces has:

1.Run the world's largest prevention studies discouraging smoking and binge drinking amongst school pupils.

2.Run a successful international study on the surgical management of early mouth cancer (3 previous attempts in Europe, South America and Asia had failed to study sufficient patients).

3.Conducted 2 National Surveys examining the causes and treatment of Facial Injury in 14,000 UK patients to find better ways of preventing and treating these injuries.

4.Funded laboratory research conducted by PhD students on the genetics of cancer and stem cell behaviour in cancer.

5.Funded Psychology PhD students to determine ways of improving the emotional and functional outcomes of trauma, deformity and cancer patients.

6.Built up a unique bank of tissue and blood collected from cancers linked to the patients' treatment outcomes. Therefore we can study the tissue knowing whether the cancer is aggressive. This should enable researchers to find markers that will help doctors tailor treatment more accurately to each patient's needs.

7.Set up a National patient telephone help line where patients who have had treatment ("Buddies") talk new patients (who have contacted FSRF) through the whole treatment pathway to alleviate their fears.

8.Started courses for medical and dental students on how to do clinical research with patients.

9.Set up an electronic diagnostic service for general doctors and dentists so that cancer patients can be seen more rapidly by the best surgeon for the condition in their local area (SFDADS). A side benefit is that patients who do not have cancer can be reassured more rapidly that they don't have a serious condition.

10.Organised 4 free public conferences (800 attendees) at London's South Bank and The Science Museum on Stem cell research, tissue engineering, Face Transplantation, and the ethics and justification for clinical research.

11.Set up an innovative lecture progamme where surgeons, patients and alternative scientific disciplines cover a topic for 90 minutes.

12.Investigated better ways of managing patients with pre-cancerous areas in the mouth using non-invasive monitoring techniques.

13.Organised tours for the "Saving Faces" Art exhibition around the world educating the public about what is and isn't possible with modern facial surgery, and that people with disfigured faces can lead normal and fulfilled lives.

14.Set up a tissue engineering group with the intention of growing replacement bone from the patients own stem cells.

Company Contact:

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