

Combating cancer, injury and disfigurement in the most socially important part of our bodies – the face and mouth



Saving Faces Newsletter

Summer 2014



Invitation from our Chief Executive

This year we are running two really exciting fundraising events in the City of London on Sunday the 21st of September. Come and join us if you can.

A 10K sponsored walk along the banks of the Thames, passing through areas steeped in history. Many famous buildings will be open to the public on this day so you can break off and go inside.

A City Treasure Hunt

- Form a team of family and friends then test your skills in our City Treasure Hunt and explore this beautiful and historic part of London.
- See the Guildhall; Pudding Lane where the great fire of London started; the wonderful markets at Smithfield and Leadenhall; the innovative Lloyd's building – And so much more (but I don't want to give away any more clues!!).
- Start and finish at Paternoster Square in the shadow of St. Paul's Cathedral.

REGISTER NOW to secure your place while substantial early bird discounts apply.

YOU CAN ALWAYS DONATE MORE IF YOU WANT.

SEE YOU THERE!!



A Brilliant Year for Saving Faces

The most exciting and dramatic news of the year is that Saving Faces has collaborated with 3 national surgical specialties to create a world first! **A National Centre dedicated to researching how best to prevent and treat facial and mouth diseases, injuries and disfiguring conditions. This National Facial Oral and Oculoplastic Research Centre, (NFORC) which Saving Faces (SF) funds has no equal anywhere in the world and will be studying the treatment of 2.5 million patients a year to define best treatment practice**, I'd like you all to share in the excitement NFORC has generated in the surgical and research community in the UK and around the world and support it as best you can. There's a special section of the newsletter devoted to the Centre and its first 12 month's achievements (see page 3).

We've got great news about all the research Saving Faces has done and is about to publish and there's a summary of that on page 4.

There's other terrific news:

- Saving Faces work improving UK patient care was recognized by a National Bevan Prize for Health and Wellbeing award. Our Chief Executive, Professor Iain Hutchison also received an individual award.
- Saving Faces work was recognized once again in a parliamentary debate – this time on domestic violence
- Our PhD students have also been winning prizes.
- Patient demand for our national Patient helpline has boomed
- Our electronic diagnostic service to speed cancer referrals is in even greater demand by doctors and dentists.



Considering all the activity our charity does we offer great value for money and this is because so many surgeons and their staff act as researchers and data collectors free of charge. But, NFORC will increase our annual spend by £350,000 to a total of £800,000.

The additional £350,000 a year will be spent on:

- £60,000 to the NHS Information Centre for data collection and storage.
- £160,000 for additional research staff.
- £85,000 to make small ex-gratia annual payments to nursing and secretarial staff at 100 UK hospitals for their help assisting their surgeons discussing research with patients and collecting the patients data.
- £45,000 rent and overheads for offices.

So this is where you can help. All of you have been very generous to Saving Faces in the past either by donating or organizing charity events. You are one of 6,000 supporters on our database and a few of you are regular donors - two of you are incredibly generous making annual standing orders of £50,000 and £100,000 – we'd be lost without your support. I know many of you have other priorities, give to many charities or are retired and don't earn much money. **However, if all of you could see your way to making a regular donation by filling out a standing order for as little as £100 a year (the equivalent of £2 a week) it would solve this problem. If you can't afford this how about £50 a year – that would also help.** Of course, if you'd like to donate more you're very welcome to be even more generous!!! **Standing orders give us financial security and free me up to devote my attention totally to our research effort.** We've attached a tear off standing order form with this newsletter. You can also find these on our website. Don't forget to complete the gift aid section if you pay UK tax.

The National Facial Oral and Oculoplastic Research Centre

NFORC

(pronounced "enforce")

Most surgical treatments are relatively successful, but there is usually more than one treatment for the same condition and some are more successful than others. Unfortunately, the evidence for which treatment works best is not available anywhere in the world. Obviously, it would benefit all patients if we could correct this situation and NFORC is setting out to do just that, by carrying out "clinical audits" of treatment.

This research centre, funded by Saving Faces, is a world first. Using its research the UK will lead the world in finding answers to which treatment works best for all diseases, disfiguring conditions and injuries affecting the head, face, neck, and mouth. This revolutionary organisation will innovate and transform the lives of all patients with these conditions worldwide.

The 3 national organisations whose surgeons deal with these problems have made this possible by partnering Saving Faces to make NFORC their research unit. Their aim is that all surgeons in their organization will study the outcome of the treatment they use for every one of their patients. This level of collaboration has not happened anywhere else making NFORC unique and a world leader. We anticipate that the treatment results of 2.5 million patients a year will be available for study.

As a result of this successful collaboration **the top surgical organization in England, the Royal College of Surgeons, has chosen NFORC to be its Head and Neck Clinical Trials Unit.**

As a loyal supporter of Saving Faces you are invited to the NFORC Launch event at The Purcell Room in London's South Bank Centre on Wednesday 26th November 2014 to hear exactly what we are doing. But places are limited so book your place now using the form included.

NFORC has already started conducting vitally important research with top surgeons in their fields for common problems that have yet to be solved. We've listed below some of these and the surgeons leading them. If you have had any of these problems we'd be delighted to hear from you – you might also help by joining one of our patient advisory groups:

- How best to treat precancerous areas of the mouth so they don't turn into cancer. *Led by Prof Peter Thomson, Newcastle University.*
- How best to treat children's facial injuries to achieve least visible scarring. *Led by Ayesha Dalal, Royal Devon and Exeter Hospital.*
- Jaw joint and facial pain are incredibly common and poorly treated. NFORC will compare different treatments for this to determine best practice. *Led by Shaun Matthews, King's College Hospital and Andrew Sidebottom, Queen's Medical Centre, Nottingham.*
- Radiotherapy (RTX) is one of the 3 common treatments for cancer. RTX in some patients causes severe damage of normal tissues blighting the lives of these patients. NFORC will seek genetic markers that predict whether a patient would be better treated with less RTX because of their extreme sensitivity to RTX. *Led by Andrew Lyons, Guys Hospital.*
- Jaw fractures: Two studies comparing different treatment practices for 2 types (jaw joint and angle). *Led by Simon Holmes, Barts Hospital, London; and Peter Revington, Frenchay Hospital, Bristol.*
- Collecting information from every UK patient who seeks treatment for facial deformity and their opinion on the benefits or otherwise of the treatment they received so that it can be improved. *Led by James Gallagher, Northampton General Hospital.*
- Better ways to identify and treat neck secondaries at an early stage in patients with mouth and throat cancer. *Led by Claire Schilling, Guy's Hospital.*
- Looking at the impact of head and neck cancer on patients' long-term quality of life. *Led by Prof Ania Korszun, Institute of Psychiatry, Queen Mary College London.*
- Comparing different ways of managing eye socket fractures to determine which works best. *Led by Jonathan Collier, Chelsea and Westminster Hospital, London.*
- Comparing treatment for children with frozen jaws to see which works best. *Led by Nad Saeed, John Radcliffe Hospital, Oxford.*

Research Spotlight

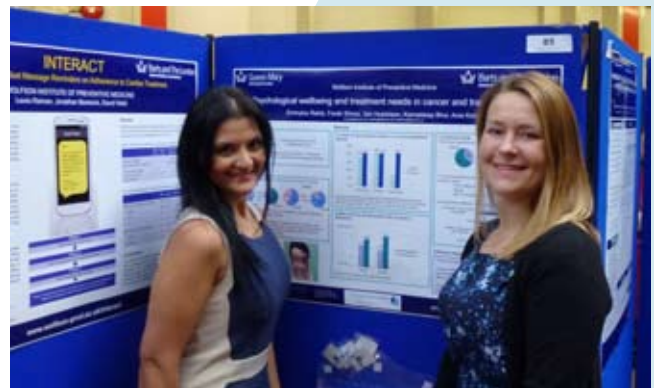
Saving Faces continues to lead ground-breaking research to prevent disease and injury and find better ways of treating these conditions:

- Surgery is still the mainstay of mouth cancer treatment. Our study on early mouth cancer, the first-ever surgical study in the UK, is now nearing completion. It is half funded by Cancer Research UK and half by Saving Faces and compares two widely used, but very different, surgical techniques for dealing with these cancers. Prof Anil D'Cruz (Director of Tata Memorial Hospital in India, one of the top mouth cancer centres in the world) has been running an almost identical study at his hospital. We are both keen to combine our data to make it the most powerful study on mouth cancer that has ever been done in the world. Our results are likely to define exactly how patients with this disease should be treated.
- We are now ready to publish the results of 3 major national studies: our schools projects on the prevention of binge drinking and smoking; and our second National Facial Injury Survey studying over 8,000 facial injuries.
- We are looking to partner The British Association of Oral and Maxillofacial Surgeons (BAOMS), The Accident and Emergency consultants and the national charity dealing with domestic violence, REFUGE, to conduct research on how best to identify sufferers of domestic violence at an early stage when intervention would prevent escalation of this violence to horrific levels. Saving Faces ideas have already been presented in Parliament by Lord MacColl, former Prof of Surgery at Guys Hospital, discussed in a debate on domestic violence and written up in Hansard.
- We have started talks with The Patients Association about collaboration around research to improve patient care.

We also fund PhD students and their supervisors. These are some of them and brief titles of their laboratory or psychology research:

- The genetics of precancer and cancer - Dr. Teck Teh and Dr Waseem Ahmed
- The identification and behavior of Cancer stem cells - Prof Ian MacKenzie
- Chemical messengers (cytokines) produced in cancer, their association with depression and the negative feedback of this depression on life expectancy in cancer – Jo Archer
- The psychological impact of cancer on patients' families – Farah Shiraz
- The psychological impact of facial trauma on patients' families – Emmy Lou Rahtz
- Pre-cancer genetics – Michael Ho
- Cancer molecular biology – Jag Dhanda

If you want to find out more detail about the results of any of these projects please contact us.



Psychology PhD students, Farah & Emmy, present their award winning poster at the William Harvey research day



Clinical fellow, Jag Dhanda

Jaia's Story



My name is Jaia, I am now 1 and a half. On Friday 20th December 2013 Professor Iain Hutchison carried out surgery to remove a haemangioma on the bridge of my nose. When I was around 6 weeks old I had many appointments with local hospitals and a specialist surgeon who dismissed any further investigation or treatment, advising that I should be monitored till the age of 10 even though my vision was being affected, my facial features started to become disfigured and it was radiating a lot of heat.

My Mummy's friend from work suggested that we contact Saving Faces which we did. Professor Hutchison met with us and diagnosed the tumour as a haemangioma. Although the tumour was benign he advised the best route of action was for surgery,

which after a lot of heartache for my Mummy and Daddy it was decided this was the best thing to do.

My operation was carried out successfully at St. Bartholomew's Hospital and after a big kiss from The Professor, I was up and about a few hours later and back home the following evening in time for my first Christmas.



Look at me now! My scar is healing fantastically and my facial features are back to normal. I am enjoying a full life and I am having lots of fun with my family especially my older sister Jasmine and brother Jayden.

We are now fundraising to raise money for this fantastic charity and help support Professor Iain Hutchison and his team carry on his amazing work. Without him I don't know where I would be today. My family have got together, they have

been making samosas and cakes to raise money, we have raised over £1000 so far! In June this year, our family friends, Carlos and Brigitte, did the Warrior Adrenaline Race (W.A.R.), getting wet and muddy on a 10K obstacle course for Saving Faces.



Professor Hutchison says "Jaia's case shows exactly why we need NFORC. There are lots of different treatments for haemangiomas but they've never been properly compared in a scientific manner. So although each doctor thinks they know what's best for their patient no doctor can actually put their hand on their heart and say what the best treatment is for each patient. Research by NFORC will resolve these dilemmas and lead to better outcomes for all facial and mouth conditions".

A heartfelt thank you to all our patients, fundraisers, research collaborators and supporters

Research today saves faces tomorrow



help us cut down costs
(not trees!)
send your email address to
info@savingfaces.co.uk

Facial Facts:

In the UK every year
18,000 people develop head and neck cancer
4 million people have a facial injury
125,000 are serious and affect young people
15,000 require surgery for facial deform-ty

You can use this form to make a single donation or a regular commitment to Saving Faces. We will be able to reclaim tax paid on all your donations if you complete the simple gift aid declaration below.

Personal Details

Title _____

Full Name _____

Address _____

Postcode _____

Telephone _____

Fax _____

Email _____

Single Donation

I enclose a cheque for the sum of £ _____
made payable to Saving Faces

Standing Order Mandate

To (your bank's name and address) _____

Your Bank Account Number _____

Your Sort Code _____

Please pay The Facial Surgery Research Foundation - Saving Faces (**Santander, sort code 09-06-66, account number 40769363**) £ _____ on the _____ day of 20____ and thereafter on the same day of the following **months/quarters/years** (delete as applicable) until further notice, making _____ payments in all.

Signed _____ Date _____

Gift Aid Declaration

I am a UK taxpayer and would like Saving Faces (the FSRF) to reclaim the tax paid on this and any other donations I make until I tell you otherwise*.

*You may cancel this declaration at any time by notifying the charity.

Signed _____ Date _____

Legacies

By making a will and leaving a legacy to Saving Faces you will help us to continue our research work and ensure that patients in the future receive the best treatment. If we are a beneficiary of your will, any money left to us is untaxable and therefore of extra value to us