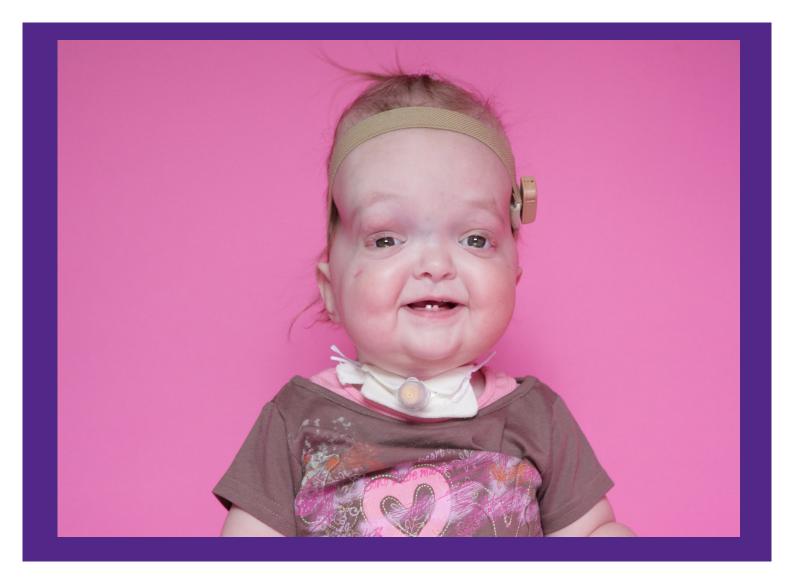


# Face Value update report

Revolutionising craniofacial surgery





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Front cover image: Lena was born with craniosynostosis. In June 2011, at age 19 months, she underwent a major operation that removed much of her skull, which was then reshaped and rebuilt before being placed in position. Now aged three, Lena is a happy, playful little girl

Above image: Isobel was born with Pfeiffer's syndrome. At just four months old, she had an operation to enlarge the bones in her face that weren't growing as they should and a specially made frame was attached to her skull, which she wore for six weeks to gradually stretch the bones. The operation was a great success and Isobel is now at home, but visits Great Ormond Street Hospital every two months for check-ups

### Introduction

Face Value is a five-year craniofacial surgery research programme led by top craniofacial surgeons Mr David Dunaway and Mr Owase Jeelani that aims to revolutionise surgery for children with craniosynostosis. With the help of generous supporters like you, we are on our way to reaching the programme's fundraising target of £1 million.

Children with craniosynostosis are likely to need a series of operations to help improve both the medical and cosmetic aspects of their condition, which is the result of the premature fusion of different sections of the skull. This means the skull is unable to grow in affected areas and can lead to severe pressure on the brain, learning difficulties, eye, breathing and feeding problems.

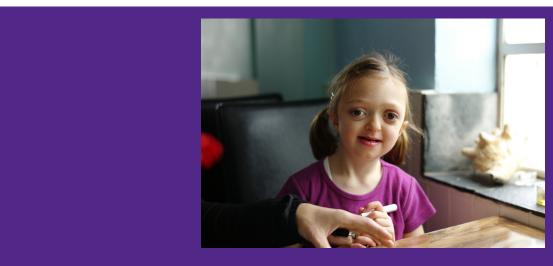
The Face Value team at Great Ormond Street Hospital is undertaking an ambitious programme to develop new techniques and equipment to improve the precision of craniofacial surgery. Better surgery will mean a better chance in life for these children.

This report aims to introduce you to the Face Value team, update you on progress to date and outline the exciting plans for the next year and beyond.

Images below: Oscar, Stanley and Zoe







### The Face Value team



Mr David Dunaway

Consultant Plastic and Reconstructive Surgeon
and Head of the Craniofacial Unit at Great

Ormond Street Hospital



Mr Owase Jeelani
Consultant Paediatric Neurosurgeon at Great
Ormond Street Hospital and Honorary Senior
Lecturer at the UCL
Institute of Child Health



Dr Alessandro Borghi
Post Doctoral Biomedical Engineer,
involved in Nitinol spring and distractor
design

### Meet Silvia Schievano



Dr Silvia Schievano
Senior Lecturer in Biomedical Engineering
at UCL Institute of Child Health, involved
in Nitinol spring and distractor design

### What role do you play in the Face Value team?

I am a biomedical engineer by training and I have spent the past 10 years working in a clinical environment. My technical expertise, together with my understanding of the clinical issues involved, can help link the patients' needs, doctors' ideas and the engineering required to develop a set of innovative craniofacial devices.

### Why did you want to join the Face Value team?

I joined this project because I truly believe that it has the real potential to benefit patients in the near future. The development of new devices for craniofacial surgery will make an important difference to the way surgery is carried out and in outcomes for patients.

### What are you researching?

My main research interest is the application of engineering methodologies to study the human body. I am currently working on the development of minimally invasive devices for cardiovascular and craniofacial applications, and on the improvement of computer simulations to accelerate device development and enhance safety in the first-in-man procedures.

### What are you expecting your research to focus on over the next year?

In the next year, we will focus on studying the mechanical properties of the spring device currently used in clinical practice, and of the cranial bone to outline the engineering/clinical requirements for the new generation of devices. At the same time, we will work on new spring designs with different geometries and materials and we will test the first prototypes in computer simulations. We will be looking at the use of a metal called Nitinol, a nickel-titanium alloy, which has shape memory and super-elastic characteristics.



Freida Angullia
Surgical trainee and Face Value's first PhD

Freida is studying geometric facial morphometrics and surgical planning in craniofacial syndromes and joined the team to begin her PhD studentship in January 2014. Freida has previously volunteered with David and Owase and everyone is delighted that she has decided to become a fully-fledged member of the team. We look forward to updating you on the progress Freida has made in your next update report.

## Support team

### Intellectual property & medical devices support



Dr Chris Williams – UCL Business PLC (UCLB)

UCLB is responsible for managing and exploiting intellectual property (IP) arising from both Great Ormond Street Hospital (GOSH) and the UCL Institute of Child Health (ICH). Their work aims to maximise the positive social, health and economic benefits of discoveries made at GOSH and the ICH. UCLB's team of highly experienced business manager's work closely with researchers and clinicians to bring technologies from invention to market.

Dr Chris Williams is working closely with Mr David Dunaway and Mr Owase Jeelani to provide IP support on the development of the novel bone distraction devices. The team are also being supported by a specialist subsidiary, UCLB Devices Ltd to provide support around the regulatory aspects of the project.

### Managerial and administrative support

Gemma Molyneux and Steven Kimberley

The Face Value team are ably supported by Gemma Molyneux and Steven Kimberley.

Gemma Molyneux joined Great Ormond Street Hospital (GOSH) in September 2013. In her role as Clinical Research Facilitator at GOSH, Gemma provides dedicated support in research management throughout the entire project lifecycle, identifying external funding opportunities and governance in clinical research, and making sure that research carried out by the team is compliant with the Department of Health regulations.

Steven Kimberley actively supports the laboratory based research activity of the team, assisting with the purchase of high quality equipment and administrative needs of the staff.

The work of the support team means that the Face Value team are able to concentrate on the day-to-day research project.

### Associated with the Face Value team

Dr Allan Ponniah – Senior Plastic Surgery Trainee. Dr Ponniah has been working on the Science Museum data to produce a computer model of the variation in the normal face using novel mathematical techniques such as principle component analysis (PCA). Dr Ponniah is currently based at the Royal Free Hospital but has retained an honorary position at Great Ormond Street Hospital to continue working on this project.

Cliff Ruff – from UCH's Medical Physics and Bioengineering Department. Cliff is supervising the creation of a mathematical model to describe normal and syndromic faces.

Femke Staal - Msc student from Erasmus MC collaborators. Femke is developing a computer model of skull abnormalities in Crouzon syndrome.

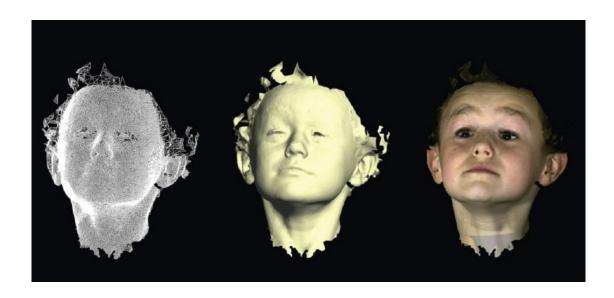
# Key objectives

Research and development will focus on:

- Pioneering new, and less cumbersome, devices to surgically move the skull and face
- Advancing our understanding of the anatomical problems of children with craniosynostosis to enable precise computer simulations to plan a child's surgery
- Improving the accuracy and safety of craniofacial surgery by investing in high-end equipment and new endoscopic systems



## Me in 3D project



The craniofacial team from Great Ormond Street Hospital joined forces with the Science Museum, University College Hospital and the Eastman Dental Hospital and Institute to launch a new project to create the largest database of face shapes in the world, which ran between January and April 2012.

The Me in 3D exhibition was an exciting public event that took place at the Science Museum in London where participants had their photograph taken in 3D to help researchers try to understand the complex differences in tissue structure that make up everyone's unique facial shape. High-tech cameras were used to collect 12,000 three-dimensional scans of people's faces.

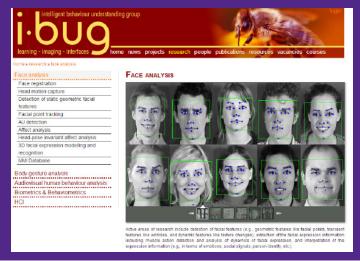
"As we're all different, it's very hard to define what a normal face should look like," said Owase Jeelani, speaking about the project. "This project provided a unique set of data, which allowed us to come up with a system for defining landmarks across a child's face."





The project appeared online in a number of articles, including BBC Online and Wired.co.uk





## Progress to date

### Mobile 3D camera (pictured above left)

Thanks to the generosity of the supporters of Face Value, the team were recently able to purchase a mobile 3D camera. The camera will allow 3D photographs to be obtained as part of routine clinical practice, used in the outpatient clinics, operating theatres, inpatient wards and other associated clinical areas to capture 3D images at different stages of a child's treatment. The advantage of the handheld 3D camera is its portability and adaptability to the moving child, which reduces patient and carer inconvenience of attending a prespecified location and reduces any distress in having to keep the child still.

#### Recruitment of Face Value research participants

In order to recruit more participants to Face Value research, the team recently made an application to the Research Ethics Committee to seek permission to invite children treated within the Craniofacial Department at Great Ormond Street Hospital to take part.

During the course of a child's treatment, many imaging techniques are used to assess each child's medical needs. By increasing the number of participants in the project the team will be able to gather more data and improve their understanding of the changes that occur following a child's treatment and how best they can use this information to improve outcomes.

#### Me in 3D software development

The Face Value team has entered into a collaboration with i-bug (http://ibug.doc.ic.ac.uk - pictured above right) to develop the computer software to carry the data received through the Me in 3D project. Each photograph collected as part of the project will be 'land-marked', which involves putting marks on geographical points of the skull, and the same points will be marked on each photograph. Measurements between points will then be taken and will provide data on what is 'normal/average' with respect to the structure of the skull and face. i-bug is a research group based at the Department of Computing at Imperial College and the group has considerable experience in developing computer software and facial analysis.

### **Publication successes**

The team has already had a number of successes in research papers over the past year, including one called *Integration* of *Image Guidance and Rapid Prototyping Technology in Craniofacial Surgery*, which was published in the International Journal of Oral and Maxillofacial Surgery. Within the paper, David Dunaway, working in collaboration with clinicians at King's College London Hospital, Newcastle Medical School and the Cavendish Imaging, describes the benefits of preoperation planning and rehearsing surgical procedure in the laboratory using the latest imaging technologies. Modern imaging technologies have the potential to reduce the risk of unexpected events during surgery and offer the advantage of knowing the full extent of the defect, allowing sufficient time to plan the reconstructive surgery.

### **Springs & Devices**

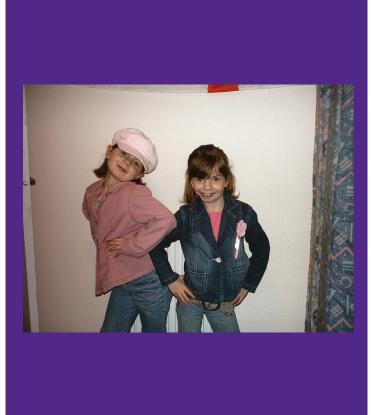
Over the last three years the team has been using stainless steel springs and devices to surgically correct facial abnormalities. They have collected data about these, both three years before and three years after surgery, to understand, from an engineering point of view, how the springs and devices work. They have learned what beneficial changes these devices have, how they change the shape of the bone and also where improvements need to be made. Silvia and Alessandro are developing, with their engineering backgrounds, new designs of springs to improve the effects of these devices. The team has been approached by German company KLSMartin (http://www.klsmartin.com/?L=2), which specialises in the production of medical devices. Our team will be meeting to discuss a possible collaboration in which they will manufacture the stainless steel springs and support the process of CE marking (where the springs are assessed to confirm they meet EU safety, health and environmental protection requirements) to turn them into marketable 'kits' that can be sold for use in surgical procedures.

## Anticipated research timeline

- Design and testing of Nitinol 3D distractor summer 2014
- Analysis of Me in 3D facial scans winter 2014
- Analytical software tool for automated facial landmarks winter 2014
- Shape memory distractors (Nitinol) for human use on research basis winter 2014
- Development of endoscopically-assisted technique for less invasive craniofacial surgery using the new distraction devices 2014
- Commercial production of spring distractor spring 2015
- Shape memory distractors suitable for general use 2017

Image below left: Oscar with his mum, Nicola
Image below right: Chloe was born with Goldenhar sydrome, which affects the heart and the face







# Meet Fiona

### Age 7

Fiona is seven years old and was born with Nager syndrome, a rare disorder of which there have only been about 90-100 reported cases. Her jaw was not developed properly, which affects her breathing and eating. She also has trouble with her hearing and gripping things in her right thumb.

In 2010 and again in 2011, Fiona underwent distraction surgery to encourage bone growth between the plates in her skull, to move her jaw forward and ultimately to enable her to completely open her mouth and breathe normally. As well as needing distraction surgery, Fiona is fed through her stomach, has a hearing aid and has had an operation on her thumb to help her grip. She has also had surgery to treat reflux.

Once the distraction surgery has been completed, her surgeon, Mr. Ayliffe, will need to operate on Fiona again as she requires her jaw joint to be built. They will use her rib to make this joint.

Fiona is a very happy little girl and when she comes into hospital for appointments, she is always full of beans and likes running around. Her sister Lila comes with her whenever possible and they like playing in the playrooms in the hospital.



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