Saving Faces

The charity for research into the prevention and treatment of oral and facial diseases and injuries

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Selected National and International Press Cuttings from the Launch of 'Saving Faces'

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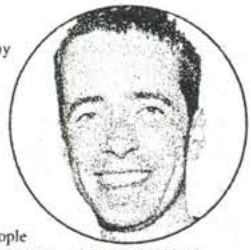
CURRICULUM SPECIAL
SUMMER 2000

Facing the world

Henry Ekpe



Artist Mark Gilbert

"My face is my fortune," sang the coy maid in the nursery rhyme. But for all too many people their face becomes their misfortune as others eye them askance.

Each year, a million people attend casualty with facial injuries. Two thousand people annually contract mouth cancer. A similar number are born with facial deformities and 15,000 develop abnormalities during childhood. Saving Faces, a new charity set up by Ian Hutchison, consultant oral and facial surgeon at the St Bartholomew's and Royal London Hospitals Trust, aims to raise funds for the prevention and treatment of oral and facial diseases.

Pop success by teen beauties Daphne and Celeste for a song called *U.G.L.Y* points to society's intolerance of deviations from the facial norm: "*When looks were handed out you were last in line/Your face looks like where the sun don't shine/Did you fall off a building and land on your head/Or did a truck run over your face instead ... You're Ugly!*" All good fun, say the duo, but no joke for someone such as barrister Henry de Lotbiniere (bottom left). Twelve years of operations to remove cancerous tumours have saved Mr de Lotbiniere's life but left him with a flesh-covered lump where one eye used to be and a crater instead of half his forehead. "I feel passionately that it is important to face the world and say that I am the same person that I ever was, even though my face is altered," he says.

An exhibition of paintings by hospital artist-in-residence Mark Gilbert records the faces of sufferers from maxillo-facial disease before, during and after treatment. In his pictures the depth of each person's humanity transcends the map of the face. Sometimes treatment corrects the conditon completely. Sometimes sufferers have to learn to live with it.

Sue Morgan-Elphick (bottom right) is a pretty young woman who underwent extensive surgical treatment to correct growth distortions during childhood. A year's orthodontic treatment and many hours of invasive surgery, which left her face held together with six titanium plates, gave Sue "the real me again. I now face the world with a spring in my step".

Henry Ekpe, a psychiatric nurse from Nigeria, underwent five operations to remove what was considered a benign facial tumour. He saved up to visit Ian Hutchison for reconstructive surgery. Mr Hutchison discovered that the tumour was in fact an osteosarcoma which, having invaded the right eye, nose and temple in two places, was advancing into the brain. In a gruelling 23-hour operation, the surgical team removed the whole right side of Henry Ekpe's skull and face and replaced it with bone from his rib and muscle and skin from his back. In 1996, the tumour recurred on the other side of his face and more of the jaw had to be removed. Today Henry Ekpe – "an absolutely terrific guy" says Ian Hutchinson – works as a charge nurse in a psychiatric ward, is married with a young child, Jerry, and about to start a master's degree in nursing at Brunel University.

Beauty is, as they say, only skin deep.

VICTORIA NEUMARK

Saving Faces, PO Box 25383, London NW5 2FL, tel: 020 7485 5945, e-mail: savingfaces@mail.com. Exhibition tours the country from September

MARK GILBERT

Main picture: 'Henry E and Jerry' by Mark Gilbert
Below left: Henry de Lotbiniere
Below right: Sue Morgan-Elphick

GEOFF FRANKLIN

The Mirror
Thursday June 29 2000
www.mirror.co.uk
32p

Health Zone

Jill Palmer's medical casebook

They screwed my face back together

METAL PLATES AND 28 BOLTS REBUILT RHONDA'S LOOKS

RHONDA Gibbs stared in the mirror in disbelief. She hardly recognised the rebuilt face that was looking back at her.

For the first time in years, she looked "normal".

The bone deformity which had totally disfigured her face had gone.

The long and complex operation that involved breaking her jaw and nose and reconstructing them using screws and metal plates had been a success.

"I was absolutely delighted and I still am," says Rhonda, who lives in Croydon, Surrey, with her husband Russell and their two-year-old daughter Molly.

"I had to keep looking at myself for months just to convince myself it was me.

"It had been a difficult choice to undergo such major surgery, but when I see myself now I know it was worthwhile."

Thirty-year-old Rhonda's abnormality developed when she was a teenager.

Her lower jaw continued growing much longer on the left than on the right, making her face lopsided and disproportionate and preventing her teeth meeting properly.

Her nose was pushed to one side. Her upper jaw and cheekbones had failed to grow and had sunk inwards.

By the time Rhonda reached 19, the deformity was making it difficult for her to eat.

She suffered extreme pain and there were grating and clicking noises whenever she moved her jaw.

Her odd appearance was also emotionally damaging the once-outgoing and confident teenager.

In desperation, she went to her dentist for help.

He referred her to the maxillo-facial surgery unit at St Bartholomew's and the Royal London Hospital, which specialises in treating facial, mouth and jaw diseases and deformity.

First, Rhonda had to wear heavy braces on her teeth for a year to move them into the correct position.

Then, in an intricate and complex six-hour operation, surgeon Iain Hutchison completely rebuilt her face.

He broke her upper and lower jaw and repositioned them. He removed excess bone, broke her nose and re-lofted it in the right place.

He used a bone graft and metal plates to wedge her cheekbones out, and screwed her jaws back together.

In all, he had to break her skull in seven places.

Rhonda still has six metal plates and 28 screws holding her new face together. They will stay there for the rest of her life.

TO AVOID external scars, Mr Hutchison worked from the inside, making cuts inside her mouth and peeling back her skin to reveal her skull.

When she came round from the anaesthetic in intensive care, she was covered in tubes and drains. Her jaw was wired together and her face had swollen to three times its normal size.

She needed morphine to relieve the pain and had to be fed through a drip because she couldn't open her mouth to eat or speak.

Her mum later admitted that the first time she saw Rhonda after the surgery, she fled the room and burst into tears.

Rhonda was too frightened to look in the mirror until four days after the surgery.

She says: "All my friends and relatives were saying how well I looked, but I was too scared to look.

"It was a terrible shock when I went to the hospital bathroom and saw myself in the mirror for the first time.

"My whole face was horribly swollen and I had these awful wires holding my jaws together."

Her jaw was still clamped together when she left hospital five days later, but she learnt to make herself understood through gritted teeth.

She prepared regular meals which she liquidised and sipped through a straw.

"The food tasted OK, but it looked awful," she says. "I longed for a proper dinner."

After two months, the wires were removed. Over the next five months the swelling gradually went down and she could see her new face properly for the first time.

"I could not get used to myself, and kept looking in the bathroom mirror and in shop windows as I walked past," she says.

"People whom I had known for years would walk past me in the street and not recognise me.

"As a child, I looked like my brother and sister, but as I grew up my appearance became totally different.

"Suddenly, my face has been put back to how it should have been and I look like one of the family again.

"When I see old photos now, it seems strange that I looked so different.

"I am really pleased with the outcome and my friends all tell me I am much more confident now.

"It was certainly worth all the pain and discomfort, although I have to admit that I didn't think that immediately after the surgery."

Mr Hutchison explains: "Facial disfigurement can make people introverted and withdrawn during adolescence as well as affecting function.

"Rhonda has a very bubbly personality, and surgery enabled her to blossom.

"She was not hideously disfigured, but her jaw had grown abnormally and the middle part of her face had not grown at all, so her face was lopsided and hollow.

"I had to break and reset several bones in new positions to push out the cheekbones and fit the lower jaw to the top of the face. A computer helps to plan how to set the bones, but the final adjustment can be made only when the patient is on the operating table.

"A millimetre movement can make a big difference, and I have to judge whether it looks right or not.

"The screws and plates remain in the face permanently.

"They can be removed, but unless they are causing pain or problems there is no point in more surgery to take them out."

Two thousand children are born with severe facial defects in the UK every year and another 15,000 develop abnormalities during their childhood and teenage years, as Rhonda did.

ANOTHER 4,000 people are diagnosed with mouth cancer, and up to a million more suffer facial injury caused by accidents or assaults.

Mr Hutchinson has now set up Saving Faces – a charity to fund research into the prevention and treatment of oral and facial diseases, injuries and deformity.

It was launched yesterday with an innovative art exhibition showing paintings of patients before, during and after surgery.

The charity aims to improve the detection and treatment of mouth cancer by co-ordinating data from the 38 UK maxillo-facial surgeons specialising in the disease.

It also hopes to run prevention projects to cut the number of mouth cancers and facial injuries and improve surgery for facial deformity.

It is also collaborating with the Football Association in looking at the causes and effects of facial injuries in football.

● PLEASE send any donations to: Saving Faces, PO Box 25383, London NW5 2FL.

CHANGING FACES..

Rhonda's odd, lopsided appearance before the operation (left) meant she lacked confidence and self-esteem.

But her looks were transformed after surgeon Iain Hutchison completely rebuilt her face in a six-hour operation.

Six plates have been fitted into Rhonda's skull, each secured by four screws, plus two long screws on each side of her mouth (right). These will remain intact for the rest of her life.

DAILY EXPRESS
www.express.co.uk
SATURDAY JULY 1, 2000 50p

Picture: DOUGIE MORRISON

ART THERAPY: Mark Gilbert has lived and worked at a London hospital, painting studies of patients before, during and after facial surgery

Face paintings

ART: A surgeon and a portraitist have joined forces for a project that is both powerful and educational. By **Jay Iliff**

GESTURING at one of his paintings – a huge canvas, blood-red and not immediately recognisable as a human face – Mark Gilbert says: "Apart from being a war artist, there's nothing more powerful than this." You can see his point. This is a picture, raw and gory, of a person's face under the surgeon's knife; the accurate record of one critical moment in the saving of a life.

Gilbert is a 30-year-old Glaswegian, and a painter involved in a unique project. Officially artist-in-residence at the Royal London and St Bartholomew's hospitals in London, almost all of his work involves patients of Iain Hutchison, one of the country's leading oral and facial surgeons.

Hutchison treats people with mouth and facial cancers, as well as injuries and deformities. It is an area of medicine which he says needs more research and more resources, and this week he has launched Saving Faces, a charity to help realise those aims.

Gilbert's work is an integral part of the campaign. Over the past year he has immersed himself in hospital life, sleeping in a nurses' hostel and working in the tiny room in Hutchison's department that serves as a studio. There he has produced some 80 paintings, which will be seen in a touring exhibition culminating at London's National Portrait Gallery in spring 2002.

Mark Gilbert is a portrait artist, but these are no ordinary portraits; by definition they are faces disfigured by disease, injury or genetic accident. His subjects are depicted before treatment and after it – and sometimes in the course of the surgery itself. This means that Gilbert has had to sit in on operations, sketching and taking photographs, becoming almost part of the team.

"When I first went to the theatre I was petrified, having seen the photos and the slides," he says. "But it's different in real life – the first time I was in there I just found it incredibly moving, because you are so aware of the suffering and situation of the patient.

"Sometimes there is the most amazing tension; other times it can be surreal, with Johnny Cash music being played in the background. You become sensitive to all the different moods – it's a very intense kind of experience."

Despite the subject matter, his work is neither bleak nor distressing. The pictures are compelling and convey a positiveness that photographs could not. "I would hate to think that all I was doing was illustrations," says Gilbert, who, before this, taught art at Benenden, the girls' public school.

"Hopefully, my experience in the operating theatre and my relationship with the patients come to inform the pictures. I realise there's a power in the images which almost supersedes how they are actually painted. The unique thing is the access I have had to all the different aspects of the patients' treatment, which is a privilege."

Deformity of the face is particularly wretched, since it is our faces which transmit our identities to the world. To agree to sit for Gilbert's pictures at all must have taken a certain courage – and it took Hutchison months to get the idea passed by the hospital ethics committee.

"I started out with a rather nebulous idea," the surgeon recalls, "but Mark's work has become a kind of bridge, a link to educate people about our work. I wanted to educate the public about what was possible with modern facial surgery. The kind of surgery we are doing with some patients today would have killed them 12 or 15 years ago.

"I also thought that Mark's paintings might have a cathartic effect on patients, helping them come to terms with their facial appearance. But he has done far more than I ever expected – he has captured the emotional travel of patients as they progress through major life events." There could even turn out to be therapeutic benefits: "In some cases they have told Mark: 'I never looked at photgraphs of myself after the operation, but since seeing the paintings I can look at myself again.'"

> *'My first time in the operating theatre was so moving'*

Hutchison hopes that Mark's work will give focus to Saving Faces, which the surgeon launched on Wednesday at the National Portrait Gallery with the help of Chris Smith, Secretary of State for Culture.

"It will campaign to raise funds for research into the prevention and treatment of oral and facial diseases as well as injuries," Hutchison says. "It will be the only charity in the UK devoted to these aims. We need to discover the best surgical treatments. We also want to stop kids smoking, which is a major cause of mouth cancer."

There are other aims, too: "We would like to be able to employ a psychologist and a psychotherapist – we are not only concerned with curing people, it's also about improving their quality of life."

As for Mark Gilbert, there is no question that he has been enriched by his experience: "In the beginning I was nervous, but the patients actually have far more self-confidence and strength than I have – and if this project proves to have some psychological benefit for the patients, that would be terrific. It's been an incredible year, and there's no doubt it has made me a different artist."

● *Send donations for Saving Faces through your own bank or any HSBC branch to: HSBC Bank plc (Saving Faces), Kentish Town Branch, sort code 40-04-03, account number 31371045*

Lettera da LONDRA

di PIER PAOLO PITTAU

Il pittore in ospedale: quando l'arte è terapia

L'ARTE COME terapia, come strumento per rompere il tabù della deformità prodotta dalla malattia o da un incidente, e per educare il pubblico, dice il pittore Mark Gilbert, sulla natura dell'intervento chirurgico destinato a cancellare o a correggere la deformità. Gilbert è il pittore "in residence" del Royal London Hospital di Londra, dove è stato chiamato da uno dei maggiori specialisti britannici in chirurgia maxillofacciale, Iain Hutchison. Da poco più di un anno Gilbert, trentenne di Glasgow con esperienza di insegnamento in una public school, vive in ospedale, dove ritrae i pazienti prima, durante e dopo l'intervento. Ha ormai collezionato una ottantina di quadri in cui è narrato il dramma emotivo dei pazienti con cui ha un contatto quotidiano. In settembre le opere lasceranno l'ospedale per un lungo giro in Gran Bretagna, ed infine torneranno a Londra nella primavera del 2002 per essere esposte alla National Portrait Gallery per tre mesi. Dietro a tutto ciò c'è un progetto per la cui realizzazione Iain Hutchison ha creato una organizzazione senza scopo di lucro, "Saving Faces". «Volevo – dice il chirurgo – far conoscere alla gente il nostro lavoro, far sapere ciò che è possibile fare con la moderna chirurgia. In più, i ritratti di Mark hanno un effetto catartico sui pazienti, li aiuta a riconciliarsi con il loro aspetto fisico». In alcuni casi, racconta Iain Hutchison, pazienti che hanno subito vari interventi hanno detto a Mark: «Non ho mai guardato a foto mie dopo l'operazione, ma ora, con questi ritratti, riesco a guardare nuovamente a me stesso». "Saving Faces" raccoglierà, con il "tour" dei quadri, fondi per la ricerca sulla prevenzione e il trattamento delle deformazioni della bocca e del volto. «Vogliamo sviluppare – dice Hutchison – il miglior trattamento possibile, ma ci batteremo anche per spingere i giovani a non fumare: il fumo è una delle maggiori cause di cancro alla bocca».

Un'opera di Mark Gilbert

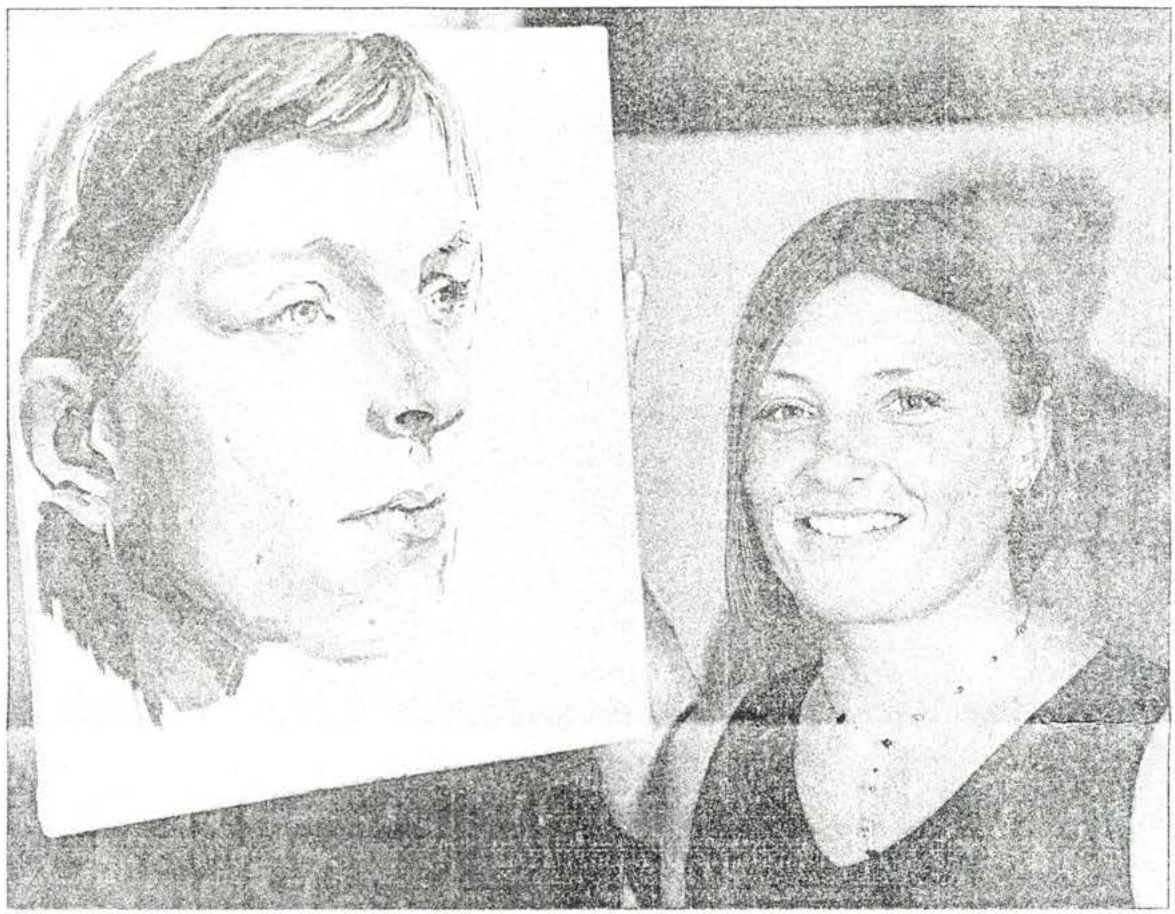
The Daily Telegraph

Tuesday, June 27, 2000

An outspoken surgeon is helping those with facial disfigurements. **Christine Doyle** reports

The future is looking better

Picture JIMMY GAXTON



In the picture: Antonia Danby, a patient, with a portrait of herself before surgery from the launch exhibition of Saving Faces

FROM the breast to the brain, and the lung to the prostate, it's hard to think of a body part that does not have a charity dedicated to promoting its own medical interests.

A surprising exception is the face. Cosmetics companies may seduce us into spending small fortunes on making the best of our features, but this counts for little if your face is disfigured by disease or an accident, damaged by a violent attack, or distorted by unusual growth of bones.

The shape of the jaw or nose can be critical to emotional stability, as Sue Elphick, a 33-year-old nurse discovered as a child. "I always felt I was an ugly duckling. My bones seemed to grow at different rates. My lower jaw and chin protruded and curled up until I was able to touch my nose with the tip of my chin. My cheek bones flattened, and soon my face looked like a crescent moon.

"I was called names as a child and for many years was extremely sensitive about how I seemed to others. I avoided social gatherings and I would always sit in the corner so I could look at my reflection. My first husband was no help and made me feel more ugly and down**trodden, but inside I knew** I was not really like that. There was a braver, more confident personality trying to escape."

Like many fellow sufferers, she found few organisations to turn to for information or support, and "friends and family gave me conflicting advice about surgery".

From tomorrow, however, the face will have its own national charity. Called Saving Faces, it will be devoted to research into the prevention and treatment of oral and facial diseases and injuries. It will be launched — appropriately — at the National Portrait Gallery by Chris Smith, the Secretary of State for Culture, Media and Sport. The charity will mark its debut with an innovative exhibition of paintings of patients from the Royal London Hospital, in the East End.

Saving Faces is the realisation of a 10-year vision for Iain Hutchison, a maxillofacial surgeon at the Royal London. One of the charity's major aims is prevention. "Extraordinarily, it is as if the face is invisible. Where are the campaigns, like those for breast and skin cancer, to alert people to the early signs of mouth cancer? How many people have any idea that cancer of the mouth affects as many people as cervical cancer or melanoma? And that it can be caused by smoking?"

Mr Hutchison has a mission to educate, which he believes might be achieved by shock tactics. "We carried out a pilot study in an East End secondary school. I gave a 12-minute talk to the 200 or so pupils in each year. A 28-year-old patient being treated for mouth cancer came with me. I showed graded slides of the mutilation that can be caused by surgery. They gasped. Eight in 10 of them had never heard of mouth cancer.

"I told them that if everyone in the room smoked, half of them might die of a tobacco-related disease. The young man with me told them he started smoking at the age of 11. There were more gasps."

Opinion, he accepts, is divided over the lasting effect of shock tactics. But one month later, 50 per cent of the smokers at the school had stopped. "We are just about to go back for a one-year follow up," says Mr Hutchison. "This is only a pilot project, but Saving Faces has set up the UK Oral Cancer Research Group of 58 young maxillofacial surgeons and our plan is to rope them into a nationwide study covering 76,000 secondary school children. That will be the real test."

Another plan is for young surgeons to talk to school-children about alcohol-related injuries. "Children often don't believe their teachers — or the health education posters," says Mr Hutchison. "I believe some straight talking from young men and women whose faces have been seriously injured in a drink-related road accident or assault, and also from those who have to repair the damage, could have an impact."

On the surgical front, Mr Hutchison is equally outspoken. "We do not have enough surgical 'gold standards' for oral surgery. Maxillofacial surgeons are extraordinarily dedicated but, like many surgeons, they tend to believe in their own techniques. We do not know for certain what might be best and there are few trials to guide us." Saving Faces wants to fund a trial centre where maxillofacial surgeons will record details of major cancer and other surgery. "The aim is to compare and assess the operations and raise standards across the country."

Sue Elphick's abnormal facial development falls into the middle of a spectrum, with cancer at one extreme and wrinkles at the other. Mr Hutchison believes those in the middle often get a poor deal in life and that more should be done for them. "About 15,000 children might benefit from surgery to correct deformities which can worsen with age."

Today, Sue is a pretty young woman, who says she "emerged from a cocoon" after major — and gruelling — surgery. "By chance, I was working in the same operating theatre as Mr Hutchison. So I asked him what he could do for me." There followed a year's orthodontic treatment to correct teeth in readiness for surgery. During the long operation, Mr Hutchison broke Sue's upper jaw and broke her flattened cheek bones and resculpted them with grafts from her own hip bone. Six titanium plates hold her new face together.

Sue, who will be present at tomorrow's launch, is happily remarried with two small children. "The operation gave me freedom. My friends always supported me, but now I am the real me again. I face the world with a spring in my step.

"To those who might think such major surgery is a response to today's increasingly perfectionist society, Mr Hutchison insists that "serious growth distortions can blight life" — a sad fact which is being confirmed by a Saving Faces research study in which people are asked to respond to photographs of abnormal and normal features. Medical psychologist Paul Farrand, who is leading the study, explains that early results suggest, as expected, that we make snap judgments on the basis of looks alone.

Rhonda Gibbs, a 33-year-old florist, always used to look depressed and miserable. Her lopsided appearance, says Mr Hutchison, "Her nose had grown to the left and her lower jaw to the right, among other irregularities. "As a child I was fine," she says. "The changes started in my mid-teens. For years, I thought you just had to put up with the face you had." Surgery transformed her, says Mr Hutchison. "Now, her cheerful spirit and personality shine through and a ripple smile back."

Other projects in the pipeline include a collaboration with the football Association to investigate facial injuries during play, the establishment of one-stop neck lump clinics, and the use of alternative treatment to speed recovery after operations.

One thing is certain. Tomorrow's launch will put a new complexion on the usual interpretation of "face saving".

Antonia's story

FOR more than a year, Antonia Danby draped her hair over her right eye. She was hiding a lumpy cartilage-like growth, which was rapidly expanding from her eyebrow downwards to create a shelf-like overhang. It also threatened the sight in her right eye.

When I meet her, she is holding a portrait painted several months before the operation which eventually removed her growth. It was painted by Mark Gilbert, a Glasgow artist, who is the Saving Faces artist-in-residence at St Bartholomew's and the Royal London facial surgery unit.

His work is an unusual art therapy project. The portraits of patients at different stages in treatment — and during operations — reflect the conflicting and changing emotions that accompany disfigurement and traumatic surgery.

Antonia, 32, a graphics production supervisor, felt immensely vulnerable to prying eyes as her lump grew. "There were many curious comments and I began to understand what those with more severe disease have to deal with."

Many patients find the paintings of themselves therapeutic and, funds permitting, Saving Faces plans to study the benefits. One man with cancer took photographs of his portraits to help him communicate his anxieties to his family.

The tiny studio at the Royal London is crammed with paintings, including one of Henry de Lotbiniere, a barrister who has lost an eye to cancer. He wears his wig and gown and exudes both composure and a sense of humour.

Gilbert aims to demystify complex and sometimes mutilating surgery: his paintings show the human face behind the cold, clinical reality.

Unfair treatment

PETER NICHOLLS

Maxillo-facial surgeon Iain Hutchison in front of paintings of his patients that were commissioned by his charity, Saving Faces

A series of shocking cases of malpractice has left the image of consultants at an all-time low. As they await tomorrow's unveiling of the Government's plan for the health service, Valerie Grove **finds that most of them are highly dedicated but feel grossly undervalued**

You have been hit over the head by a baseball bat; found a lump on your neck; been thrown through the windscreen of a car. Your child has meningitis. You are in labour, or in chronic pain, or in a life-or-death limbo, lying on a stretcher, on a trolley, on the operating table. At such moments none of us has any doubt about who deserves to be highly valued and rewarded by society — and it is not the chief of your local water board, nor a dot-com entrepreneur, but the man or woman in the mask, scrubbing up.

Consultants have been having a terrible press. The Bristol heart surgeons, the "butcher" Rodney Ledward, and now another blundering, incompetent gynaecologist, Richard Neale — all these highly publicised stories have been of malpractice, and the impression lingers of supercilious fat-cats coining it while waiting lists lengthen.

"MPs say NHS consultants should not do private work" runs a headline in the current *British Medical Journal*. Following the Commons select committee's inquiry, the Health Secretary Alan Milburn will reveal his ideas on consultants' contracts in his National Plan this week.

But there are 23,000 consultants in the NHS. Almost a third do no private practice. Their days are long, their rewards comparatively modest; they take life-affecting decisions — and to most of their patients, their worth is incalculable. After years of studying and interrupted nights, registrars start on £28,000 a year, consultants on £45,000. They work in hospitals that are like battlefields. Are consultants the scourge of the NHS, or its linchpins?

Iain Hutchison, maxillo-facial surgeon, consultant at Bart's and the Royal London hospitals, is happy to show me his pay-slip: the NHS pays him £70,000 a year — which includes a merit award, a bonus many consultants never reach. He thinks this is "not unreasonable". But is it reasonable recompense for restoring lives?

Hutchison reconstructs faces, chiefly after removing cancer tumours. You may have heard him on Radio 4's *Midweek* last week, modestly recounting how he also rescues faces "smashed to smithereens" in accidents, or horrendously disfigured from birth. His normal day starts (after rising at 5am to do his paperwork) with ward rounds at 8am, and finishes at 7pm. We spoke at the end of a stressful week in which he'd carried out three 12-hour operations on successive days. He is called out at night

Continued on page 4