Thank you to everyone who was interviewed for, or gave permission for their picture to be used in this review, as well as the many members of the UCL Institute of Child Health and Great Ormond Street Hospital staff who helped during its production.

Please visit www.ucl.ac.uk/ich/research-ich or www.gosh.nhs.uk/research-and-innovation for an online version of this review.
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Director’s report

This year has seen many great achievements, with a number of our researchers being acknowledged for their contributions to improving the landscape of children’s health. Partnership has also been at the forefront and will continue to be crucial in our ongoing success.

Professor Waseem Qasim, with Professor Adrian Thrasher and Doctor Paul Veys, and their teams, made an important breakthrough in the use of a novel gene editing approach to provide a treatment for a child with relapsed leukaemia. This breakthrough made the international news because of its implications for the future treatment of more children.

We have also recently learned of our success in being awarded the National Institute for Health Research (NIHR) GOSH Biomedical Research Centre for five years from April 2017, with Professor Thomas Voit, as Director. Underpinning this achievement is our commitment to research into rare diseases in children and the close partnership between the ICH and GOSH. This further five years of funding will enable us to develop new therapies for diseases where the treatment options are currently very limited.

Individually, our staff have similarly had very substantial achievements. Three new professorships were announced in June 2016, with effect from October 2016: Professor Helen Bedford, Professor David Dunaway and Professor Sara Mole. In addition to his professorship, Professor David Dunaway was honoured with a CBE by Her Majesty the Queen in the 2015 Birthday Honours List. Professor Tim Cole also received the Rank Prize for Nutrition as recognition for his excellence, dedication and outstanding contribution to the field.

We have appointed new heads to two of our five research programmes: Professor Monica Lackhangpau now heads Population, Policy and Practice, and Professor Paul Gissen now heads Genetics and Genomic Medicine. Honorary Fellowships have been awarded by UCL to Ms Ruth Kennedy for her outstanding philanthropic contribution to paediatric palliative care research, and the ICH honoured three fellows for their outstanding contribution to child health: Baroness Tessa Blackstone, Dr Jane Collins and Professor Catherine Peckham.

I will end where I started, with the importance of partnership. In addition to our strong partnership with the hospital, we have a close partnership with Great Ormond Street Hospital Children’s Charity, and we are working with them on their five-year strategic plan for research. It is our shared vision to improve children’s health, and with the commitment and determination of our staff to achieve this ambition, I believe we will do so. It is a pleasure to write this report to you every year, and share with you some of the groundbreaking research taking place at the Institute.

Professor Rosalind Smyth
Director
UCL Great Ormond Street Institute of Child Health
Great Ormond Street Hospital (GOSH) continues to strive for clinical and research excellence in all it does. Our ambition is to give every child and their family the opportunity to take part in, and benefit from, cutting-edge research, while continuing to provide them with the very best care and patient experience.

This review provides just a few examples of the broad spectrum of research undertaken by GOSH and our academic partner, the renamed UCL Great Ormond Street Institute of Child Health. This partnership, and the people and projects it nurtures, continues to drive progress across a wide range of disciplines, from work on wide-scale genome sequencing carried out by Professors Lyn Chitty and Maria Bitner-Glindzicz, to the research of Professor David Dunaway and Mr Owase Jeelani to revolutionise craniofacial surgery and improve the lives of children with conditions like Apert or Crouzon syndromes.

Our ability to push the boundaries of what is possible in the care of children has made global headlines this year. At the end of 2015, in a world-first, Professors Waseem Qasim and Paul Veys used ‘molecular scissors’ to edit genes and create designer immune cells to treat one-year-old Layla’s ‘incurable’ leukaemia. Layla continues to do well and we have now treated a second child. The technique behind this new cell therapy holds much promise across other fields of research, including in the treatment of debilitating conditions such as epidermolysis bullosa.

Being a world-leading children’s hospital is also about the experience we provide for patients, and our research extends to this arena. This includes work carried out by Dr Suellen Walker into the management of pain and that of Dr Kate Oulton to ascertain whether children with learning difficulties have equal access to high-quality care.

All of our research must be underpinned by robust processes for capturing and analysing data. This year, we have commenced work on our digital strategy, including looking at options for a new electronic patient record system. This will provide real-time information to support clinical decision-making and will improve the experience our patients receive. It will also play a key role in driving research by providing unprecedented ability to access clinical information and outcomes.

We cannot hope to make the breakthroughs we want for our children without working in partnership. This year, working with Great Ormond Street Hospital Children’s Charity, we partnered with the Evening Standard and Independent newspapers on a Christmas appeal that raised more than £3.5 million for projects at the hospital, including research. The campaign also allowed us to raise awareness of the importance of paediatric research, particularly in the area of rare and complex diseases, and the difference investment in new technologies and therapies can make in powering new discoveries and treatments.

Our most important partners are the children, young people and families who come to our hospital. This year, more than 3,000 patients agreed to take part in research projects. While some of them may not directly benefit from the findings, their contributions will help generations of children to come. I would like to thank each and every patient for helping us to develop new and better treatments and, by doing so, give many more children the chance to fulfil their potential.
Division of Research and Innovation report

Great Ormond Street Hospital (GOSH) and the UCL Great Ormond Street Institute of Child Health (ICH) joint Division of Research and Innovation believe research is core to care.

GOSH is a leading children’s Research Hospital and our vision is for research to be an integral part of the working lives of our staff, patients and families we treat and see. Our aim is for research to be fully integrated into our mission to improve the treatment and outcomes of our patients. During this past year we have begun to implement a Research Hospital initiative, designed to achieve this goal.

One key component of the Research Hospital is to continue to build expert research infrastructure and capacity, essential to this is our National Institute for Health Research (NIHR) Biomedical Research Centre and our Somers Clinical Research Facility. The NIHR Great Ormond Street Biomedical Research Centre (BRC) has been awarded £37 million for a further five years to drive forward translational research into rare diseases in children. The Centre is the only one of its kind in the UK dedicated to paediatric research. The successful application was submitted as part of an ongoing partnership between GOSH and the ICH. We have also been awarded £8 million from the NIHR for five years’ funding to support our Somers Clinical Research Facility.

We continue to look for innovative ways to build our research capacity and through an increase in our research revenue and with matched funding from the Great Ormond Street Hospital Children’s Charity, we are now able to invest £1.2m annually in key research posts designed to underpin our research capacity. Our expectation is for these research posts to become sustainable through a continued increase in research revenue.

Training the next generation of clinical academic leaders in paediatric medicine is also a component of our capacity building. The appointment of Dr Kate Dutton as Clinical Academic Programme Lead for Nursing and Allied Health Research in June 2014 has been pivotal in our commitment to promoting the training of non-medical researchers. Kate, a Senior Research Fellow in the GOSH Centre for Outcomes and Experience Research in Children’s Health, Illness and Disability, provides mentorship and promotes research career pathways for nurses and AHPs at GOSH and UCL and has developed and implemented a strategy to develop and sustain clinical academic roles for nurses and AHPs in the organisation.

Our most successful training scheme for nurses and AHPs has been our internship programme; this releases individuals from their clinical duties to gain research experience in the BRC. Interns are then encouraged to apply for a NIHR doctoral or post-doctoral fellowship training. This has resulted in two successful fellowship applications in 2016: Lesley Katchburian, a Clinical Specialist Physiotherapist at GOSH has been awarded a NIHR Clinical Doctoral Research Fellowship and Dr Elaine Cloutman-Green an Infection Prevention and Control Practitioner at GOSH who has been awarded a NIHR Clinical Lectureship.

A second key component of the Research Hospital is the roll out of a generic consent programme designed to help us learn from each and every patient we see. We have initiated a pilot generic consent process focussing on the use of excess tissue and blood samples and associated data for future research. This will allow us to develop a unique cohort of rare disease paediatric samples and appropriate consent for future research.

Ensuring we engage our patients and families in our research programmes continues to be a priority and in 2015 we established a new parent advisory group for research. We continue to look for new ways to involve our patients and this year we co-funded ‘Under the Microscope’ an arts research project conceived and led by artist Sofie Layton. The work explored how paediatric patients and their families interpret medical information and understand disease, and culminated in the creation of installations exploring Severe Combined Deficiency Syndrome and congenital heart disease. The project generated awareness of complex and invisible health conditions and the application of new technologies, such as 3D printing and gene therapy, to a wider audience. Importantly, the project focused attention on the way researchers and clinicians communicate, offering a unique role for different ways of engaging with patients and the public around science.

Ensuring our research is of high quality and meets all regulatory requirements is essential. At the end of 2015, as part of a regular cycle of inspection, the Medicines and Healthcare Products Regulatory Agency came to review the conduct and management of clinical trials of investigational medicinal products at GOSH. The outcome was very positive with the inspectors recognising the excellent work undertaken at GOSH and the continuing progress we have made in improving our processes since the last inspection in 2011.

We have seen a number of successes in 2015/16 some of which you will read more about in this report. Through close collaboration with the Clinical Research Network, GOSH was the biggest single contributor nationally to the children’s theme delivering 2,144 recruits, and contributing more than 1,600 recruits to other themes, totaling more than 3,000 patients.

GOSH is the lead Trust for the North Thames Genomic Medicine Centre and is making an important contribution to the 100,000 genomes project. The North Thames Genomics Medicine Centre is contributing over 25% of rare disease samples nationally, Professor Bitner-Glindzicz talks about this nationally important initiative later in the Review.

We saw continued success with the NIHR Senior Investigator Programme. These posts represent the country’s most outstanding leaders of clinical and applied health and social care research. Professors Francesco Muntoni, Jane Sowden, Helen Cross and Russell Viner were all successfully appointed as new NIHR Senior Investigators.

Our commitment to supporting clinical research has been acknowledged by the NIHR with two of our investigators receiving awards from the NIHR Clinical Research Network for their contribution to clinical research. Dr Ri Liesner has been recognised for recruiting the first global patient in a haemophilia study designed to evaluate the safety and efficacy of a recombinant fusion protein. Dr Anna Martinez was recognised for recruiting the first European patient into a phase 3 Epidermolysis Bullosa trial.

We look forward to reporting further exciting developments next year.

Ms Emma Pendleton
Deputy Director of Research and Innovation

Professor David Goldblatt
Director of Clinical Research and Development
Our year in figures – a joint report from GOSH and the ICH

Collaborations with more than 180 organisations in 73 countries worldwide.

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“I loved working in paediatrics, but I was increasingly drawn to understanding how the circumstances of children’s lives affect their health, now and in the future. Her aim is to inform national and local policies and services so that they can be changed to promote health, and to reduce the individual and economic burden of health conditions in the future. Working with researchers at the Universities of Liverpool, York, Melbourne and Adelaide, her work could affect the lives of children in the UK and globally.”

“Most of our work relates to the children you see walking up and down any street in the country. We mainly use a research dataset called the Millennium Cohort study that has a nationally representative sample of all children born at the turn of the century. It collects information not only on children’s health, but their lives more generally. We’re very lucky in the UK to have this and other cohorts: they’re a great resource.”

Professor Law’s work focuses on common conditions like obesity, mental health problems, and injury, and health-related behaviours such as smoking and physical activity. These childhood problems and health-related behaviours link to health in adult life. Her team’s research tries to unpick the inter-relationships and pathways between the circumstances of children’s lives and how they develop the capacity to be healthy now and in the future.

“The challenge is in trying to analyse the complexities of modern families’ lives over time, she says, and identify potential changes that are amenable to policy action.” For example, Professor Law’s research has investigated how employment in families may influence children’s health. “When employment changes, all sorts of other things change – income, child care arrangements, the amount of time to spend at home... Our research aims to inform national policies, for example, around child care, to maximise their potential to promote child health.”

In a bid to help children combat obesity, Professor Law ran a population level study, investigating whether provision of the MEND programme, a popular weight management service, was equal for all children. “We know that these services are needed more in disadvantaged areas, where there are proportionately more overweight children,” explains Professor Law, “so we wanted to see if children from these areas were getting equal access to them. What we showed was that they did have fair access, but when they used the service, they didn’t lose as much excess fat as their more advantaged peers. We now need to look at why that is and make services better for these children, otherwise we risk increasing health inequalities.”

Obesity and other conditions related to health behaviours are also becoming increasingly important in low and middle income countries. “In many cases, the economic, social and physical environment isn’t conducive to healthy living,” she explains. “These countries are seeing an explosion of diseases that you previously only expected to see in richer countries. We don’t know much about how they arise or how they’re best prevented or treated in these settings, so I am working with funders to develop research evidence, capacity and collaborations that will address the future burden these diseases will have across the world.”

This is an important area of research, and we ignore it at our peril says Professor Law. “We need to increase the scale and ambition of prevention research and pay it the attention it deserves. At stake is the future health of our children and society, not just in the UK, but globally.”

Tackling health inequalities for children, now and in the future

Professor Catherine Law is committed to ensuring that all children are given the best chance of a healthy life. She is using large research datasets to build evidence that can change policies affecting the future health of the population. As well as her own research, Professor Law works with national government and funding agencies to commission research and is an advocate for public involvement in population science.
Specialising in immunology and blood stem cell and bone marrow transplants, Professor Waseem Qasim has made incredible use of what he calls a “tsunami” of technology, which is already helping to change the face of clinical care in some of the hardest-to-treat conditions.

“I’ve found myself in the ideal arena for deploying experimental treatments,” he explains. “Because our work involves collecting cells from a donor or a patient, that gives us a chance to improve them, to modify and engineer them.” Working with children with abnormal immune systems, leukaemias and blood disorders, his aim is to treat these conditions by either ‘fixing’ the child’s own cells or by giving them healthy cells from a donor that have been engineered to overcome the condition. A number of trials are already under way using disabled viruses for gene therapy, and his lab is working on the next generation of reagents.

For Professor Qasim, new technology is paving the way for some exciting work. “We now have reagents that allow us to edit certain parts of the genome and to modify their function. Together with other strides in technology using disabled viruses, we’re suddenly able to do things we couldn’t imagine a few years ago.” The biggest step came just over a year ago, when Professor Qasim and the transplant team led by Doctor Paul Weps took the leap and tried gene editing therapy on a child with what was then termed ‘incurable leukaemia’. They engineered donor immune cells – T-cells – and primed them to destroy the leukaemia cells. They then further edited them to stop them reacting against the patient and also to be invisible to one of their key transplant drugs. Getting permission for use in a patient when it hadn’t gone through the normal approval steps proved challenging, but the data and arguments were persuasive. “There were some important questions to address, but because of the situation with these patients, making use of the hospital’s special licence and getting exceptional permission to use this experimental treatment was the only option available,” explains Professor Qasim. “Now we’re at a stage where we’ve treated two patients. One is a year out from treatment and doing well, the other is six months out, and the formal trial has also accelerated and is now open. Over the coming years, we will need to address the best way to apply this type of treatment.”

This technique holds great promise for other fields of research too. Professor Qasim is already working on using the similar platforms to treat other leukaemias, inherited immune diseases, and other conditions such as the debilitating skin disease epidermolysis bullosa.

Over the next few years, the path of Professor Qasim’s work is clearly mapped out. “The Phase 1 studies of the modified T-cells are now under way. We’ll learn from each of the patients, as they’ll all respond differently. At the moment we’re treating one type of leukaemia, B-cell leukaemia, but we think we can use this for other forms too. That work is ongoing and we hope to move them into trials as soon as we can. We will also want to make the treatments more widely available, not just in this hospital but across the UK, in both children and adults.”

“It’s an exciting time for us: we’re seeing the benefits of this work, we know there are improvements to be made, and we’re doing them,” explains Professor Qasim. “But there’s also an enormous wave of technology and reagents coming down the line and we’ve got to be ready.”
People power – solving problems with population research

Professor Monica Lakhanpaul is passionate about searching for answers to challenges in healthcare by speaking to the people who know best: the patients and their families. She is an internationally renowned population researcher with a drive to ensure that children and families are empowered to be at the centre of the research process.

“While I was a clinician working in inner city Leicester, I realised we could learn so much by listening to the problems families regularly faced and to the solutions they came to us with. Sometimes as researchers, we need to stop and ask people: ‘How can we help you?’ This kind of research can make a difference to large numbers of children, and what may seem like a small solution can have major impact on improving people’s lives – that’s rewarding. For me, when you see this true partnership between researchers and the community, when you’ve given patients and families a voice, and they’re shaping the research direction and finding the answers, that’s what’s most inspiring.”

Professor Monica Lakhanpaul, Professor of Integrated Community Child Health at the UCL Great Ormond Street Institute of Child Health

“Population research is all about working with children and families to give them a voice and looking at new models of care to help keep unwell children at home wherever possible,” explains Professor Lakhanpaul. “It’s about bringing together different disciplines to achieve that, so not just medicine, but education, public health and the social sciences. We’re breaking down those barriers so that we get the best outcomes for children.”

Her work particularly focuses on using collaborative participatory methods with marginalised communities and has already had big implications for some of those involved.

Asthma still claims the lives of 1,400 people in the UK each year, including children. Many of these deaths are preventable. The South Asian community are three to five times more likely to be hospitalised by the condition. So working in collaboration with social scientists and psychologists from De Montfort University and University of Leicester, Professor Lakhanpaul set out to ask the community to identify for themselves where the issues lay. They also asked what priorities they would want the NHS to focus on, with the aim of improving management of the condition at home, reducing admissions to hospital.

“What we found was that there was a lot of mistrust and confusion around the diagnosis of asthma,” she explains. “People didn’t understand the information being provided to them and it did not address their concerns. Children were experiencing problems at home and not being taken to the doctor because parents were worried they might be criticised. What we needed to do was work with the families, including extended families, to tailor the information and education.”

Another of Professor Lakhanpaul’s projects focuses on babies and toddlers (age six months to two years old) in the Bangladeshi community of Tower Hamlets. It aims to understand how parents feed their children so that they can co-design ways to support better diets, preventing problems such as obesity, dental cavities and ultimately diabetes and cardiovascular disease later in life. “What was interesting about this project is that the community identified the problem,” says Professor Lakhanpaul. “We then worked with them to develop a plan. Now members of the community have been trained as researchers and are leading the recruitment of study participants. She anticipates that this model of participatory research could be used to reach out more effectively to other communities.

An additional focus of her work is Down’s syndrome. “Children with Down’s syndrome come in to hospital with complex issues like breathing problems,” she explains. “We want to better understand how they are currently being managed so that, if needed, we can develop pathways of care or new interventions to keep children in the comfort of their own home. For example, we can look at whether they have been given antibiotics before they’re seen in hospital. This will help determine if giving them early on, or even as a preventative measure, could help keep these children at home. A lot of the current guidance for clinicians is not evidence based, so we hope this research will better inform practice and change the care that children receive.”

Professor Lakhanpaul believes Great Ormond Street Hospital will play an important role in population research in the future: “We are a large research hospital with experts from many different disciplines, seeing families from across the country and the world. These children have diverse backgrounds and want to work with us to make a difference. We can provide the forum in which to do this. In the future, I hope to have developed a blueprint for researchers to follow, that gives every child and their family the chance to inform and directly influence population research, helping to find answers to the questions that matter most to them.”
Amelie's story
When Amelie was just one year old, she was diagnosed with juvenile idiopathic arthritis. “Her entire life has been marked with chronic and often crippling pain that affects her whole body,” says Amelie’s mum, Caroline.

When she first came to Great Ormond Street Hospital, Amelie underwent a two-week intensive physiotherapy rehabilitation programme. Caroline says: “The wonderful team of physiotherapists, doctors and nurses have changed Amelie’s life. After years of struggling to even climb a step, now, at 11 years old, she is able to do things she always dreamed of, like sport. She even captained a netball match.”

Amelie undertook a strenuous drug regime that includes weekly doses of chemotherapy and groundbreaking new medication. “Despite all of this, Amelie is a happy child and always wears a smile,” adds Caroline.

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Professor Lucy Wedderburn, a renowned expert in the field, “and that can be a shock for the whole family at diagnosis.”

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"I trained in general medicine at Oxford, before becoming a psychiatrist at the Maudsley Hospital, and came to Great Ormond Street Hospital (GOSH) in 1985. I initially worked on Turner syndrome (a genetic disorder that only affects females). I was interested in the endocrine and growth issues, but then we noticed the behaviour of girls with Turner syndrome was unusual too. We discovered that about 30 per cent have social difficulties that are very similar to those of children with autism. That observation brought me into autism research."

Professor David Skuse, Chair of Behavioural and Brain Sciences at the UCL Great Ormond Street Institute of Child Health and Honorary Consultant at GOSH

Professor Skuse has been a pivotal part of the autism research field for a significant proportion of his career. “The first thing I’ve seen change over the years is a growing recognition that autism is not just about children with serious learning difficulties,” says Professor Skuse. “Most people now accept the idea that autistic behaviours exist on a continuum – a spectrum of severity – between clinically significant problems and minor difficulties. Twenty years ago, our research group came up with the world’s first screening test that demonstrated the existence of such a continuum. I discovered that there was a much higher proportion of affected girls than ever who came to the attention of clinicians. Most of them were overlooked because they had normal-range IQ. When I said at the time that 90 per cent of children with autism spectrum disorders were not intellectually disabled, many of my colleagues thought I was misguided. But now, most children diagnosed with autism spectrum disorders in the UK and USA do have intelligence in the normal range.”

Recently, they have been seeing more and more girls – after years of chronic under-recognition, the tide is finally turning. “The main reason is that affected girls are able to compensate for their social difficulties and disguise them in everyday life. We are now leading the way in devising new approaches to diagnosis,” he concludes.

DUE in part to his groundbreaking work in autism, Professor Skuse was successful in applying to lead a new study, this time on the genetic risks associated with intellectual disability (ID). The IMAGINE-ID study is a strategic Medical Research Council initiative to promote research in this area of need, which affects more than 200,000 children in the UK. They are aiming to identify children with ID caused by a particular change in their genetic makeup, a copy number variant, or CNV. Currently, about 35,000 children each year have their DNA screened for genetic anomalies by NHS Regional Genetics Centres. “About 15 per cent of that 35,000 have been identified as having a CNV that gives rise to their condition, a pathogenic change,” explains Professor Skuse. “But what we currently think are pathogenic CNVs may only be the tip of the iceberg.”

IMAGINE-ID is creating a database that links genetic changes to behavioural characteristics and also aims to link up with the children’s educational and health records in the future. This will create a comprehensive data set that will be available to researchers and clinicians worldwide.

By involving every regional genetic centre in the country, they plan to recruit more than 5,000 children over the next few years and will look at their behavioural characteristics in detail. “This research program is unique. No other study of this type has been done anywhere in the world,” he says. “The reception from parents has been incredibly positive. It’s finally helping to give them the answers they’ve been looking for.”

“In addition, if we are able to identify the genes that don’t work properly, we can then build a picture of the faulty pathways of brain development. That could lead to the discovery of novel treatments and interventions in the future,” emphasises Professor Skuse.

“I think what’s exciting about our research is that much of it is in unknown territory. There is huge potential for discovery. As we identify more very rare conditions from their genetic causes, it could open the door to understanding lots of syndromes we currently know virtually nothing about.”

Demystifying autism and intellectual disability

Professor David Skuse is a world-renowned autism researcher who has recently undertaken a large study to try and reveal the genetic basis of intellectual disability.
Dr Suellen Walker is searching for answers that could help relieve long-term pain and identify the mechanisms that lead to different types of pain.

“Chronic pain can have a huge impact on children’s quality of life, particularly if it means they can’t go to school or socialise. The Pain Service at GOSH comprises a multidisciplinary team with doctors, nurses, psychologists and physiotherapists, who all work together to assess and manage pain, and also educate children and families about pain and how to manage it.” Dr Walker’s team are also involved in developing clinical practice guidelines and evidence-based protocols that are used not only locally, but also nationally and internationally. “For as many areas as possible, we want to take research all the way through from the lab to the clinic and practice changing recommendations and then look for continuous improvement: bedside to bench and back again.”

Funders
- Great Ormond Street Hospital Children’s Charity via the Louis Dundas Centre for Palliative Care
- Medical Research Council
- National Institute of Academic Anaesthesia

Tarun’s story
When Tarun was just three weeks old, he came to Great Ormond Street Hospital (GOSH). He was diagnosed with multiple pterygium syndrome, meaning he had webbing in his hands and feet, dislocated hips and elbows, and stiff knees. He had a number of operations to correct some of the affected areas. When Tarun was studying for his GCSEs he began to experience severe pain. “At one point, the pain ran up the entire length of my leg, and it would happen at random times during the day and night, lasting for hours,” says Tarun. “I was taking very strong painkillers just to get through a day.” The pain continued to cause him problems. “A few years later, I began experiencing chronic pain,” says Tarun. “I had to miss a lot of college. I couldn’t sleep with the pain and it was taking over our family life.”

Around this time, he started attending the Pain Management Programme at GOSH. “The programme taught me how to manage my pain by taking regular rests when doing new activities. It offered techniques to help me get back to sleep after particularly bad experiences. The multidisciplinary team was amazing, especially the pain psychologist – she gave me information and useful techniques for every type of pain I experienced. It was a long journey, but it’s really helped me – now I’m at university and I have managed to come off my medication completely. It’s made me feel much more independent.”
Consultant at GOSH
Genetics at the ICH and Honorary Professor of Clinical and Molecular
but they’re also intimately linked with patients and their families.
Each of the estimated 37 trillion cells in the human body has a staggering two metres of DNA bundled inside. Every double helix is made up of a sequence of molecule pairs – an estimated three billion in our entire genetic code: our genome. This genome determines everything about us from our hair colour to how our organs function. When global researchers first sequenced the entire human genome, it cost around US$3 billion. It paved a new era of medicine, but it’s only now, with the costs of technology plummeting, that this technique is finally finding its place at the forefront of medical care.

The 100,000 Genomes Project, as the name suggests, is a national project aiming to sequence 100,000 whole genomes of NHS patients with cancer and rare inherited diseases by 2017. In the case of rare disease patients, family members will also be screened. GOSH plays a lead role in the project, coordinating delivery across a network of hospitals in the North Thames region, and is currently the highest-performing centre taking part.

The benefits are multifold, explain Professor Lyn Chitty and Professor Maria Bitner-Glindzicz. “For cancer, it’s much more experimental,” says Professor Chitty. “It will give us a lot of information on the biology of the disease, and help to develop new ways to diagnose, monitor and treat cancer. But for rare diseases, it will also help to expedite the diagnosis of rare conditions, which can mean a lot to families, and also holds the promise of developing targeted, personalised treatments in the future.”

“My focus is on rare diseases,” says Professor Bitner-Glindzicz. “It’s true that diagnosis means a lot to families. Without it, they can sometimes feel as if they’re stuck in limbo. But once that diagnosis comes through, they can begin to work out what the next steps are. That can be different for each family. It could be about simply meeting more families with the same condition, or being able to have another child, or understanding the long-term outlook for the child who is affected and determining whether the disorder can be treated. And, of course,” it also helps doctors to understand how the disease is likely to progress.

“We hope that by doing whole genome sequencing (WGS), it will help to end the diagnostic odyssey for many families,” emphasises Professor Chitty. “At the moment, what normally happens when you have someone with a rare genetic condition, is that you test one gene after another. But with WGS, we can do it all in one go, removing the need for all of those genetic tests, and potentially a lot of other tests too. So not only could it give answers, but it will also mean a better patient experience and potentially money and time savings for the NHS.”

Professor Bitner-Glindzicz agrees: “It will tell us whether, in certain cases and for certain diseases, WGS should be one of the first investigations a clinician should request: We also stand to learn so much more about genetic conditions.”

It’s already having a profound impact for some of the patients involved. “In one case we were able to make a diagnosis of a rare form of epilepsy which responds to a different sort of treatment,” says Professor Chitty and Professor Bitner-Glindzicz. “We altered the child’s diet and reduced drug treatments, which improved the outcome.”

The 100,000 Genomes Project is all about bringing this kind of hope to more families and securing the future of the service with a system that is sustainable once the project ends. “I would like to hope that the collaboration we’ve established across the whole of the North Thames region will continue,” says Professor Chitty. “In the future, we hope to be able to deliver these services by collaborating in all specialties across the area. Our laboratory scientists will have to work with other laboratory scientists and clinicians, because in order to interpret the data, we have to work together as a team.”

“We’re also part of a national effort,” adds Professor Bitner-Glindzicz. “It’s our responsibility to do this and we’ve stepped up to it and will continue to do so.”

Ironing out problems, like ensuring the education of the next generation of doctors and researchers so that they keep up with the pace of technology, and stay on top of ethical issues, will be imperative. The future looks exciting. “This is a transformative project,” says Professor Chitty. “We are implementing it into the NHS as we go, but at the same time we’re developing a large cohort of patients and data for our researchers across the country to work on.”

Professor Bitner-Glindzicz is also optimistic: “I think that in the future, every child with a genetic disease should be able to get a diagnosis. That’s the dream,” she says. “Then we want to be able to link that with what we know to be the long-term outcome, so that when we give parents a diagnosis, we can also tell them what to expect. Obviously, all culminates in the ultimate hope, which is to be able to design therapies that will help as many of these children as possible.”

• Great Ormond Street Hospital (GOSH) is playing a key role in the 100,000 Genomes Project led by Genomics England. The aim is to show the value of genome sequencing, while preparing the NHS for the widespread use of the new technology.

Unravelling the genetic code behind diseases

Georgia’s story

After her first birthday, Georgia’s parents discovered a catalogue of symptoms in their little girl. She had physical and mental developmental delays, a rare condition affecting her sight, poorly functioning kidneys and verbal dyspraxia, meaning that she didn’t start talking at the usual age. Standard genetics testing gave no results and the family were told Georgia had an undiagnosed genetic condition. “I had no idea that it was possible to have an undiagnosed condition,” says Georgia’s mum, Amanda. “I thought we’d have the genetic tests, and get the answer. Being told that Georgia had an undiagnosed condition was one of the hardest points of our lives, as we felt like we were alone.”

When the family heard about the 100,000 Genomes Project they were keen to sign up. “As soon as we were told about the project,” says Amanda. “They had her genome and so the answer had to be there somewhere.”

It was almost a year before Professor Maria Bitner-Glindzicz was able to explain that they had found an anomaly in a single one of Georgia’s genes that was likely to be causing her problems. For the first time, Georgia had a molecular diagnosis for her condition.

The difference it made to the family was huge. They hadn’t given up hope for the future either. “It’s going to take time to find out more about this gene, and what it controls and affects, but I’m sure they’ll find more out,” says Amanda. “Medicine is not yet at the stage to offer genetic therapy for Georgia’s condition but we have come so far in her lifetime already that who knows what the future holds?”

The thing that motivates me is collaboration. We’ve helped to deliver a huge project with people across the country and that collaborative aspect is vital. I’m also learning as much now as I did at medical school! It’s such a stimulating environment to be in and an exciting and extraordinary challenge.”

Professor Lyn Chitty, Professor of Genetics and Fetal Medicine at the UCL Great Ormond Street Institute of Child Health (ICH) and Consultant at GOSH

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From fever to oxygen via Everest – improving critical care

Professor Mark Peters is at the forefront of changing the research landscape in critical care, a vital step in ensuring delivery of the best service possible.

Critical, or intensive, care spans many disciplines of a hospital, treating patients when they’re at their most vulnerable. Yet we lack some of the most fundamental answers to how best to monitor and care for these patients, says Professor Peters.

“Our main interest now is in trying to sort out some of the unacceptable evidence deficit in critical illness,” he explains.

Although the mortality rate in paediatric critical care is less than a fifth of that in adults, and the stays are very much shorter, the truth is that there isn’t a solid evidence base for a lot of what we’re doing. Extraordinarily, that stretches to some of the most basic things, including what to do with some vital signs.

With a mission to correct this lack of evidence, Professor Peters and his team are looking at several areas, from how to quickly predict deterioration in patients, to the correct levels of oxygen to give and even how to control fever. “Fever is a highly conserved evolutionary response to help defeat infection,” explains Professor Peters.

“Even plants get fever, so we’re talking about at least one and a half billion years of the evolutionary process. But, for some reason, in modern medicine, our first response is to try and stop it, and there’s now good evidence that that’s not always the thing to do.”

Professor Peters’ latest study will undertake work to see if a more conservative approach is acceptable to parents and clinical staff, before hopefully leading to a larger study that will answer the question once and for all. “We’ll also look at the mechanisms underlying fever, the energy cost, the genes involved, and understand the risk of allowing fever to go higher. The exciting thing is that it could be a defining change in the way critical care does research,” he emphasises.

After playing a role in a large project called Xtreme Everest, which involved taking children to altitude at the foot of Mount Everest and studying how their bodies responded to the lower oxygen levels, Professor Peters was fascinated and wanted to further understand the implications for critical care. Oxygen is vital in keeping us alive, but it can also damage the body if too much is given. “Adaptation to low oxygen is one of the key processes in critical illness,” he explains. “This newly funded work will translate into understanding if we’re giving patients too much oxygen. Since we submitted our grant, it’s already turned out to be a hot topic in adults. So we’ll be connected to the UK adult study and try to align protocols, and we should be able to understand the differences in adults and children.”

Just like all of his studies, this will pave the way for changes in care, but it’s been a journey to get more people involved in this vitally important type of research. “We’ve been able to increase the number of our clinicians that are involved in research, and that’s really satisfying, but there’s still more we can do,” explains Professor Peters.

“We’re increasingly aware of the benefits. Our research office is now physically embedded on our ward. This is essential. To succeed in this field, we need to be able to identify patients to take part in research within minutes.”

Arlo’s story

In the first few weeks of his life, baby Arlo needed three major surgeries, including a delicate operation on his oesophagus using keyhole techniques developed at Great Ormond Street Hospital (GOSH).

During pregnancy, his Mum, Rebecca, and Dad, Marcus, discovered that Arlo had a hole in his diaphragm allowing his intestines to go into the chest cavity, pushing his heart over to the right side and compressing his left lung. And on the day of his birth, Arlo was also found to have a problem with his oesophagus and two holes in his heart, which would require surgery at GOSH.

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“Arlo was in intensive care and ventilated for much of his time GOSH,” says mum, Rebecca. “We were so grateful to the staff on the Neonatal Intensive Care Unit for their support, I could see that they genuinely cared, they helped with everything from comforting Arlo to making sure we understood the medical side of things.”

After successful operations by surgeons at GOSH, Arlo is now home and doing well “I still can’t help being a little too cautious, but when I take Arlo out and I see him light up from experiencing new things I just have to calmly remind myself that he’s not ill anymore and that’s all thanks to GOSH,” says Rebecca. “Thanks to everyone there he will be able to have adventures and experience life, like any parent wants for their child.”
Dr Kate Oulton, Senior Research Fellow in the Centre for Outcomes and Experience Research in Children’s Health, Illness and Disability (ORCHID) at Great Ormond Street Hospital (GOSH)

“Being a nurse highlighted to me that everything starts and ends with patients. You see first-hand the challenges that they face. I wanted to take that a step further, and to try to change things for the better, to make the patient experience the best it could be. For me, it’s especially about equality - giving people an equal chance and an equal opportunity to take part in research, and to ensure the equality of services that we provide. We need to listen to enable us to deliver a better service for the whole family.”

Involving patients and families in improving the delivery of care

Dr Kate Oulton is using innovative techniques and resources to ensure that children and their parents have a say in how services are delivered, improving the overall patient experience.

“The research that I do is all about improving healthcare experiences, outcomes and opportunities for children, young people and their families,” says Dr Oulton. “My work particularly focuses on children who have rare or undiagnosed conditions, and those with learning disabilities, and their families.”

Along with her team, Dr Oulton has just been awarded funding by the National Institute of Health Research (NIHR) to conduct a three-year study (2015–2018) looking at whether children and young people with learning disabilities have equal access to high-quality hospital care as children without them. Parents and families were forefront in the planning and execution of the study, with the team working closely with a parent advisory group and local special needs schools to help ensure the research is conducted sensitively, ethically and using appropriate methods. The research team includes experts from GOSH, University College London, the University of Hertfordshire, and Kingston University, as well as a parent and a local special needs school. “It’s a national study and the response has been great,” says Dr Oulton. “We anticipated recruiting 18 hospitals to the first phase of the study, but we actually secured 24, including every major children’s hospital in the country.”

Their first step has been to interview senior staff at these hospitals, to determine whether they have certain systems in place, like flagging patients with learning disabilities and mechanisms that allow children with learning disabilities to communicate. “We’ve also carried out surveys of staff,” adds Dr Oulton, “comparing their experience, confidence and attitudes to caring for children with and without learning disabilities. We’ve had more than 2,000 responses.”

The next phase will be in-depth case-studies of six of the hospitals, where they will work with children and families to understand their experiences. “We’ll be interviewing children with and without learning disabilities, using creative methods to help them express themselves,” emphasises Dr Oulton. “We’ll also be giving parents electronic diaries to record their experiences. What we will then do is use this information to see if inequality exists, and if so, for who, and why. If there are inequalities, we want to know what we can do to reduce them.”

More broadly, Dr Oulton’s work is looking at improving how services are delivered to and experienced by patients and families. For example, recent funding from Roald Dahl’s Marvellous Children’s Charity has allowed GOSH to recruit, for the first time, a nurse who works specifically with children and families with undiagnosed conditions. The families themselves played an active part in shaping the role profile through a co-design phase led by Dr Oulton.

In another area, they’re looking to relieve anxiety around blood tests. “We’ve been working with Go Create! to launch an app,” explains Dr Oulton. “It takes a child on a journey through the body and gives them lots of different information about blood.”

Their aim is to know if children ultimately feel less anxious when prepared better for the test. “There’s also a distraction game built in to see if counting blood cells can help relieve anxiety during the test itself,” says Dr Oulton.

This type of work has the potential to make hospital a better environment for children and their families, and Dr Oulton is keen for more nurses and allied health professionals (AHPs) to get involved. “I’m passionate about clinical academic careers,” she says. “At Clinical Academic Programme Lead for nursing and AHP research, funded by AHPs GOSH and the BRC, my role is to motivate and support nurses and AHPs to lead on research in their clinical area. It’s a rewarding job.”
**Face Value – shaping the future of facial disfigurement surgery**

Surgeons Professor David Dunaway and Mr Owase Jeelani are harnessing technology to find incredible new ways of revolutionising craniofacial surgery. Using metals with ‘shape memory’ their work could improve the lives of children born with craniofacial conditions including Apert and Crouzon Syndromes.

In 2012, Professor David Dunaway and Mr Owase Jeelani formed a cross-disciplinary research team that aimed to change the way surgeons tackle surgery for craniofacial conditions. “Face value is about finding new ways to improve the operations we have at the moment,” explains Professor Dunaway. “These are designed to improve people’s skull and facial shape, both to correct deformities and also to improve functional issues like breathing problems, increased pressure in the skull and the vision problems that come with these conditions.”

“There are two arms of the study,” explains Mr Jeelani “One looking at better ways to describe the cranial and facial deformities which will help us better understand how to fix them, and the other looking at better ways of delivering surgery,” he adds.

First, they wanted to understand and map the human face. “As we’re all different, it’s very hard to define what a typical face should look like,” says Mr Jeelani, “We needed to come up with a system for defining landmarks across a face, so we would better understand how to improve our corrective surgery.”

To do this, they took their 3D cameras to the London Science Museum and enrolled a staggering 12,000 people to take part. “We now have the largest database of 3D images of faces in the world,” says Professor Dunaway. “What we’ve done is to use that data to build a statistical model of the average human face. We can then use it to see how anyone might vary from it.”

“ ‘The system seems to be able to predict things like age and ethnicity,’ says Mr Jeelani, “and when we looked to see if we could predict the presence of the craniofacial disfigurements typically seen in Apert or Crouzon we, could. We now have a tool to accurately describe how their faces differ from the general population.” This gives the team an unprecedented opportunity to understand exactly how to correct disfigurements and also a way to tell them where surgery has gone well and what they could do better. The system has already proved useful in the treatment of Apert Syndrome, where the face is often repositioned, or moved backwards. “Our operation in the past used to bring the whole face forward,” explains Mr Jeelani, “but using the new system we’ve understood that what we really need to do is move the central part more than the outer. So we’ve been able to improve the operation and divide the face in the middle, then bend it, before moving it forward, so the central part comes out more.”

The improvements didn’t stop there. The team also used the model to help them make a further refinement to surgery which involved dropping down the section around the eyes. “It’s proving to be a helpful tool for continuous improvement,” says Professor Dunaway. Other pilot projects are already looking at whether this could be a useful, non-invasive diagnostic tool in the womb.

When it comes to the second part of the study, the better delivery of surgery, collaboration has been key. “We work with a team of engineers headed by Doctor Silvia Schievano, Lead for Biomedical Engineering at the Centre for Cardiovascular Imaging, at the UCL Institute of Cardiovascular Science,” says Mr Jeelani. “We want to look at devices made from shape memory metals,” he adds. “These are metals that you can programme into a certain shape and they will always try to go back to that shape,” explains Professor Dunaway. “We can use these implants to gradually bend the bones to the shape we want. This would be a great step from what we have now where children often have to have an external frame attached, so their face is gradually pulled to the shape we want over a period of several weeks.”

This technology is still some way of being used in surgery, but the team have been able to make improvements to an existing technique which uses metal springs to help re-shape the skull. “There is a condition called sagittal synostosis, where children have narrow, long heads,” explains Professor Dunaway. Surgery is needed to make the head wider and shorter. “This is usually a major operation but what we can now do is make a small incision on the top of the head, make two cuts in the bone and place two springs in the parallel cuts,” he adds. “The springs then gradually push the head wider, shortening it at the same time. The amazing thing is that the children can go home the next day and come back after three months to have the springs removed. That’s done in a day. So in terms of surgical economy it’s great, but also for patients and their families too. They’re not exposed to the risks of a major operation, or the pain associated with it. There are lots of benefits.”

This is just the first stage. The pair hope to make further improvements to the device going forward and they hope to apply the same technology to reshaping the face, not just the skull. “We’ve already made some progress and can turn a flat piece of metal into a nose, but we still have a long way to go,” he adds. Ultimately this would be much better for patients. “If we succeed, not only will we be able to do more complex shape changes, but we’ll also be able to implant a device and send somebody home for three months while it does its work, rather than them being in hospital for three or four weeks while we adjust an external frame.”

The future is bright. “Over the next few years we’d like to see the completion of the shape memory metal devices, so we can begin using them in facial surgery and we’d also like to perfect the statistical model of facial form so it becomes a prediction and diagnostic tool,” says Professor Dunaway. “I’d also like to see a bigger team with more expertise, that can produce more devices that are really useful and in everyday use. This will help secure the future of this vital type of research.”

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- Cerebral Martini GmbH & Co KG, a company of the KLS Martin Group
- The Beckwith family and friends of Children
- Science and Engineering Research Council (EPSRC)
- Portland Hospital for Women and Children

**Stanley’s story**

Stanley was born with the rare condition Crouzon syndrome, which causes the flat plates of bone that form the skull to fuse together early in life. This interferes with the growth of the skull and distorts the shape of the head. Stanley’s airway was also affected and he still has an artificial airway that was inserted at birth.

Stanley first came to Great Ormond Street Hospital (GOSH) when he was just eight weeks old, and has been in and out of hospital ever since. His mum, Clare, has counted 18 operations in total, including four on his skull. In 2014, Stanley started to lose his balance. An MRI revealed he had developed a condition that was causing the base of his brain to push on his spinal cord. If left untreated it could have led to paralysis. “Stanley underwent a gruelling eight-hour operation to fix it,” says Clare. “It went well and, amazingly, he was home just six days later. He has such a lot to deal with, but he never lets it get him down. He is such an inspiration to us all.”

When I started my career as a craniofacial surgeon my focus was all about the technical aspects of surgery. We have an unprecedented opportunity to bring together expertise to deliver this research for the benefit of our patients. If we succeed, I hope we’ll have produced something which craniofacial units around the world can use to help the children in their care.”

Mr Owase Jeelani, Consultant Paediatric Neurosurgeon and Head of Neurosurgery at GOSH and Honorary Senior Lecturer at the ICH.
Grants and donations

Great Ormond Street Hospital and the UCL Great Ormond Street Institute of Child Health continue to receive grants and donations towards research from the following individuals and organisations.

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UK Children’s Neurological Research Campaign
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Worldwide Cancer Research (formerly known as AICR (Association for International Cancer Research))
Xoma
Young Epilepsy (operating name of The National Centre for Young People with Epilepsy (NCYPE))
Zogenix International Limited
ZonMw
The aim of the developmental biology and cancer programme is to study the key processes necessary for normal development and tissue homeostasis that are altered in childhood diseases.

- **Cancer** – to understand the molecular basis of childhood cancers and to develop more effective therapies for children with cancer, by combining basic research in cell and molecular biology with translational cancer research and clinical trials.
- **Developmental biology of birth defects** – to use techniques of genetics and developmental biology to improve our understanding of, and develop novel treatments and preventive strategies for, clinically important birth defects.
- **Stem cells and regenerative medicine** – to promote and expand translational stem cell research and harness the great potential of regenerative medicine for childhood disease.

The focus of the developmental neuroscience programme is to minimise the impact of disorders affecting the developing central and peripheral nervous system.

- **Anatomical, genetic and functional aspects of neurodevelopment** – to understand normal and pathological neurodevelopment using innovative technologies.
- **Improving neurodevelopmental outcomes** – to promote early diagnosis and improve the treatment of children with developmental or acquired disorders of the brain through robust clinical trials.
- **Shape national guidelines and policy** – to contribute to the development of national guidelines and policies, and set national/international standards of clinical care for children with neurodevelopmental disorders and diseases affecting the function of the nervous system.

The aim of the genetics and genomic medicine programme is to use genetics, imaging and biological indicators to understand predisposition to disease and what constitutes health during childhood and throughout the life course.

- **Genetics (and epigenetics) in health and disease** – to use genetics, imaging and biological indicators to understand predisposition to disease and what constitutes health during childhood and throughout the life course.
- **Gene and protein function** – to develop tools, skills and resources to elucidate gene function and to inform development of new therapies using state-of-the-art technologies.
- **Translational genomics** – to create, integrate and maintain data and informatics platforms to support genomic, proteomic and other -omic research and its healthcare applications.
- **Personalised medicine and patient benefit** – to ensure that basic science discoveries of disease mechanisms and patients’ genomes are used to best effect to improve patients’ lives. This will include better diagnostics, identification of biomarkers and targeting of therapies.

The aim of the infection, immunity and inflammation programme is to deliver world-class interdisciplinary research for children with infectious, immunological and inflammatory disease, children with life-threatening respiratory disease, children in pain and critically ill children in intensive care.

- **Molecular basis of immunological and inflammatory disease** – to apply high-throughput genetics to understand the molecular basis of these immunological and inflammatory diseases.
- **Basic immunological mechanisms** – to investigate immunological mechanisms and function in model systems and in children.
- **Pathogen action** – to understand molecular mechanisms of pathogen action through study of microbial genetics and host response to challenge.
- **Disease prevention** – to develop effective methods to enhance disease diagnosis in early childhood and use effective vaccination strategies.
- **Development of a world-leading translational research programme** – to undertake clinical trials in children with immunological and inflammatory diseases using novel therapies.
- **Respiratory, critical care and pain** – to improve the understanding of early lung disease and the pathophysiology of children with life-threatening respiratory disease, critically ill children in intensive care and children in pain, and to develop novel therapeutic and management strategies to improve their outcomes.

Research across the life course – to identify risk factors for disease, testing hypotheses on causal mechanisms and informing public health policy.

- **Address burden of disease** – to investigate common, chronic and complex conditions of children and young people, using population-based and clinical approaches.
- **Promote children and young people’s health** – to define and measure what matters for children, young people and their families, and to use this information to promote children and young people’s health.
- **Children in their contexts** – to carry out research on health services, the environment and other systems and contexts to prevent, diagnose and treat disease and to promote health and wellbeing.

The cross-cutting theme for rare diseases will harness the excellence in these fields within the programmes above and seek to:

- **Improve the lives of children with rare diseases through basic and translational research.**
- **Create greater visibility and emphasis on rare diseases by enhancing research activity, facilitating joint working between the UCL Great Ormond Street Institute of Child Health and Great Ormond Street Hospital (GOSH) and engaging with external partners.**
- **Offer tangible benefits for children with rare diseases, either at GOSH or nationally and internationally, using the latest technologies.**
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Right: six-year-old Emily on Badger Ward.