

This book is dedicated to the thousands of incredible people who take part in Children of the 90s, or have done so in the past – including those who are no longer with us.



## TWENTY ONE YEARS: OUR JOURNEY

Celebrating Children of the 90s – 1991 to 2012

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### **FOREWORD**

Congratulations to everyone involved in the Children of the 90s study. Twenty one is a significant milestone, traditionally marking the transition to maturity, a time when past choices have borne fruit and the future is more secure as a result. This is as true for the Children of the 90s project as it is for the children – now young adults, of course – who are at its heart.

Children of the 90s was not the first longitudinal cohort study in the UK but it is distinct for many reasons. Taking inspiration from previous studies and extending their approaches, the team committed from the start to continually collecting information from participants.

Unlike many other studies, Children of the 90s recruited women during pregnancy so that precise information could be gathered about the children's lives even before they were born.

Scientifically desirable as such an approach was, many people might have baulked at the challenge of setting it up and sustaining it for a lifetime. It could not have succeeded without the passion and dedication of researchers, clinicians, midwives, volunteers and, of course, the thousands of mothers who agreed to take part and their children who continue to

contribute their data. It is a hugely impressive effort and owes much to the enthusiasm that the project generates in everyone who comes into contact with it.

The 'collect everything' philosophy was not one that funding bodies were used to supporting in the 1980s and 90s. The decision to award Children of the 90s core funding – from the Medical Research Council, the Wellcome Trust and the University of Bristol – from 2001 represented much-deserved recognition for the researchers, the participants and their families.

To you, we add our personal thanks. It is a huge gift that you are providing. So much has already been learned from the study and we know there is more to come. The long-term benefits derived from Children of the 90s will help to improve people's health in the Bristol area, across the UK and throughout the world.

### Sir John Savill

Chief Executive of the Medical Research Council

### Sir Mark Walport

Director of the Wellcome Trust

### INTRODUCTION

### From Professor Jean Golding OBE

Before writing this introduction I read through this amazing and inspirational document. It was interesting to see how much had changed over the past 21 years. It took me back to my early childhood. I was born at the very start of the Second World War – when even toys were unobtainable. Mine was the generation of making do – and I remember having great fun playing with saucepans and clothes pegs! Childcare was totally different – it was thought to be very important for babies to have lots of fresh air and even cold baths. How things have changed.

In reading this book my emotions have varied from being deeply touched to being so very proud at having started such a wonderful study. Thanks to all of you we have together made a difference. When we first developed the slogan 'help us to change the world' I was rather dubious as to whether we could achieve such a thing. It needed a lot of dedication and faith from you the participants and all of the people who have worked together to make the dream a reality.

Very very many thanks to everyone taking part.



From Professor George Davey Smith

Over the last 21 years, you and your families have helped to build a 'bank of life', a unique three-generational resource that began when we recruited your mums back in 1991 and has grown to include you, your dads, your siblings and now even your children. When I took on the role of the programme's Scientific Director in 2006, I realised what a privilege it was to be steering one of the most precious scientific studies of human life ever carried out. Never before has a large group of people answered so many questions, undergone so many assessments, and contributed so much information over so many years. With your continued help, the active inclusion of all your family members and the ongoing belief of the ALSPAC team, Children of the 90s can go on changing science and changing lives for generations to come. Thank you.

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### CHILDREN OF THE 90S: WHAT WE DO

Over the last 21 years, you've been part of one of the largest population studies in the world. Children of the 90s is known as a 'birth cohort study' – it follows your lives from before birth, to adulthood and beyond. The project falls into a branch of science called epidemiology – the science of studying how people live their lives. Every time we uncover a clue about what might cause or contribute to illness, we share this information with public health workers, the Government, and other scientists. This helps to improve the well-being of the population now and in the future.

There are five key elements that underpin what we do. They are:

Representativeness: In order to be scientifically rigorous, we have to follow the lives of the same large group of people.

We chose families from the Bristol area because it provides the rich diversity of backgrounds you would expect to find across the country.

This means our results can be applied to the whole of the UK.

Consistency: Why do we ask you the same questions year on year? So we can build up a picture of all the complex factors involved in your life and monitor how those change over time. That's why we need to capture information about you as often as possible.

Complexity: It's very rare that a single, specific element of your genes, lifestyle or environment causes a specific disease – usually disease results from a combination of factors. Our researchers analyse all the information you provide using a variety of techniques to see if any of the patterns are down to bias or chance or are instead a true reflection of the links we think exist.

Accuracy: Our findings are accurate only if as many of you as possible take part – the more often we see the same pattern, the more we can be sure the conclusions we draw

from it are true. Missing data hinder this but information from people's official records help fill in some of the gaps.

Being ethical: External organisations and our own Ethics Committee review how we do things to make sure our work is fair and appropriate, and that it takes into account how you feel about being part of the study.

CHILDREN OF THE 90S IN ACTION

How we collect and analyse data





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### **HOW THE STUDY WORKS**

In order to build up an accurate picture of how your genes, your environment and your lifestyle might influence your health, we want to collect information in as many ways as possible. We can't always tell you why we're doing the things we're doing because we don't want to influence how you respond. The reason Children of the 90s is so successful is all thanks to your commitment and the trust you place in us. The following are some of the key ways in which you give us insight into your lives, your physical and emotional health and your overall well-being.

Questionnaires: These ask about your health, environment and lifestyle. We regularly pose the same questions so that we can build up a picture of your health in relation to your changing lifestyle over time.

Focus visits: These help us to gather details, particularly about your physical health. We sometimes use interviews and high-tech equipment to gain evidence that we can't collect in any other way.

**Biological samples:** Samples of blood, urine, saliva and hair provide us with biomarkers and genetic data that we analyse in light of your changing health, lifestyle and environment.

Data linkage: With your permission we collect information from official records, such as your medical or school records, so that we can try to fill in some of the gaps (if there are any) in answers you've already given.





'We have been part of this amazing experience from day one. When they asked if they could have my placenta after the baby was born of course I said yes as I really had no plans for it! After my daughter was born we had lots of questionnaires, visits to clinics, and requests for hair, toe nails, and even air from outside her bedroom window.'



'The most profound thing I recall is the kindness shown by all the centre staff. I remember peering into black boxes, and having my skin numbed with "magic cream". There was always so much to do in the waiting room, it was almost a shame when I was called through to play a funny computer game or ride on an exercise bike.'

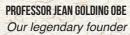


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FROM THE ALBUM

### THE TEAM THAT SAYS THANK YOU

Hundreds of scientists, researchers and core staff have worked with you over the last 21 years to make Children of the 90s the incredible success it is today. Here we put faces to the names of some of the people who want to say a big thank you to you.







PORTERS

Welcoming you on arrival



FIELDWORK TEAM

Chatting to a mum during a Focus visit



Processing and safely storing your biological samples



POSTROOM TEAM
Sending out your questionnaires
and birthday cards



PARTICIPATION TEAM

Planning events and dealing with all your queries



ADMIN TEAM

Ensuring the organisation runs smoothly



THE LEADERSHIP TEAM

Managing and shaping the future of Children of the 90s



PROFESSOR GEORGE DAVEY SMITH
Steering the scientific direction
of the organisation



### PART ONE: JOURNEYS OF FULFILMENT

### YOUR LIVES TO 21 AND BEYOND

When we first approached your mums about being part of Children of the 90s, your own lives were captured in only a bundle of cells – a powerhouse of potential. Nevertheless, we had a clear and hopeful vision that if we could collect biological, health and lifestyle data during your mums' pregnancies, and from you as you grew up, we might be able to make discoveries that would make life better for the population as a whole. We open this book with a celebration of your lives since before you were born. From mums and dads to you, the 'children', this chapter is filled with your voices, your stories and your amazing achievements.

# TWENTY ONE... MEMORIES THAT DEFINE PARENTHOOD

Since the moment you were born, your parents have guided you on your path to adulthood – but their own journey hasn't always been easy. Whether they've had to nurture you through illness, lean on you during difficult times, or learn to let you go, their lives have been filled with many moments that make being a parent the unique, precious experience it is. These are 21 of their stories.

FIRST-TIME FATHERHOOD For me fatherhood is epitomised in the memory I have of how I felt after our son was born. In one moment I acknowledged how this beautiful baby was completely dependent upon us. I was overawed by his absolute trust in us; I resolved never to betray him. I began to change from a self-centred young man to a more empathetic and altruistic adult - although I still have to work at that sometimes, all these years later.

FOOTPRINTS TO SCHOOL Parenthood, I think, is a series of letting go. On my daughter's first day at school, she knew the drill - she'd been there many times with her sister. She let go of my hand, ran and jumped onto footprints painted on the ground. Her face told me that she felt so grown up; her first steps to independence. For me, my 'baby' was moving on with confidence, looking back only to show me how happy she was.



KEEPING HIS COOL I have a terrible phobia of wasps. One of my proudest moments as a mother was watching my eight-year-old son deal with having a wasp land on his lip. I know that I would have panicked, but he kept perfectly still - he didn't flinch at all – until the wasp took off of its own accord. I was so proud of him. And of me – I'd managed to raise a son who could remain cool in the face of something that would have terrified me. He's still like that now.

You arrived at four in the morning
A limp tag of flesh wrapped for trouble.
I stood alone in a large room and stared at you.

You were bundled into an incubator and Connecting with you became second hand.

Now you breeze down the road laughing with your friends Dancing, always dancing.

Your hands an elegant disguise for survival.

The light shining from your voice, your hair,

Your face, your beautiful face.

SHOWING SELFLESSNESS

I think parenthood is defined by the selflessness of our children. My son is the youngest of three and his older siblings both have learning difficulties. While my son was growing up, both his brother and his sister needed much more of our attention – and yet he never complained. Instead he helped wash and dress his older brother, held his hand when we were out and later supported him through cancer. At the same time he became a cathedral chorister and worked his way through secondary school a year early, taking his A levels just before he was seventeen. Now he's training to become a teacher and he coaches junior rugby. He is my inspiration.



### EARLY LEARNING

I remember always consulting Penelope Leach's Your Baby And Child in the hope of finding the answers to my parenting questions. I remember my husband buying our son his first rattle and the baby throwing it across the room. I remember his love of Thomas the Tank Engine (he used to call the Fat Controller 'Dee Dat Dee Door') and how he wanted us to read the stories over and over again. I remember how he loved *Postman Pat*, shape sorters and building blocks. Oddly, though, I don't remember how all those childhood passions evolved into his love of quantum physics. To me that reveals the most amazing thing about parenting of all – no matter how we prepare them, play with them and teach them, our children will always keep us guessing when it comes to the next step on their journeys.



**HEALING BRUISES** Parenthood is defined by the number of times I've had to soothe the bruises of an extremely active son. As soon as he could walk, he lived life in the fast lane. We have spent hours in A&E together. First there was a broken collarbone when he tried to skid across a wooden floor, but hit the doorframe; then there was the fishhook he skewered through his finger. Once he was playing rugby, outings to A&E were part of our Sunday routine. He's had his ankles, knees, shoulders, ribs and soft organs manipulated or X-rayed. At 21 he's remarkably unscathed - thanks largely to all the wonderful hospital staff who have helped put him back together time and time again.

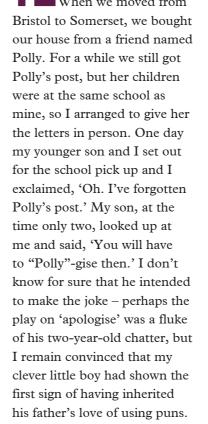
THROUGH A CHILD'S EYES

My son was not yet two. It was early evening and I was in the kitchen making dinner. He was playing quietly in the room next door. Suddenly he came running in excitedly. 'Look, Mummy, look,' he shouted, pulling me towards the front door. I opened the door and out he rushed, pointing at the sky. 'Moon, MOON.' In the still, blue sky, hung the white full moon that he had seen out of the window. It was beautiful and extraordinary, seen hundreds of times, but this time through the wonder of my little boy's eyes. 'Yes,' I said. 'Moon.' We stood in silence, hand in hand, and drank it in.

When my daughter was born, she looked perfect. Then, as she grew older, she didn't make any sounds and would communicate with me through physical gesture – when she put her thumb in her mouth and rocked from side to side, she wanted her teddy bear; when she put her thumb on her cheek, she wanted her bottle. In time a brainstem test revealed that she was profoundly deaf. We both began to learn British Sign Language and watching my daughter sign 'Mummy' was wonderful, but I longed to hear her say it too. She had speech therapy, but she was diagnosed with a language-processing problem that meant she might never be able to talk at all. Years passed and she left school at sixteen to go to residential college. There she met a wonderful speech therapist who taught her how to use Cued Speech - eight handshapes in four positions around the mouth that make the shapes of spoken sounds clearly visible and easy to mimic. Later, when she came home for the summer holidays, I was washing up and from behind me I heard someone say 'Mummy'. I shot around in disbelief. My daughter cleared her throat and said 'Mummy' again – this time much more clearly. My eyes welled up, I put my arms around her and I squeezed seventeen years of longing into that most special hug of our lives.

SIBLING MOMENTS

Parenthood and family dynamics are always changing. My daughters are three years apart. For a while the older mothered the younger, while the younger was very accommodating of the older, willingly dressing up in whatever costume her big sister and sister's friends demanded, allowing them to plaster her face in make-up and - worst of all - letting them play 'hairdressers' on her hair. It was hairdressers that triggered a turning point in the family dynamics. For the game Little Sis had seemingly about a hundred hard pink-and-blue prickly rollers, complete with pins, tightly twisted into her hair. She sat there patiently accepting every roller, only now and again exclaiming, 'It hurts.' But things were about to change. One day, after two recent bouts of the increasingly painful game, Little Sis had had enough. When Big Sis and her friend demanded that she come and sit down to have the rollers put in, she remembered the discomfort of the previous occasion and a shadow crossed her face. For the first time in her life, she looked defiantly at her bossy Big Sis and in a squeaky little voice declared, 'No. I won't.' And that was the dawn of another era of parenting.



PARTY PLANNING

Organising my children's birthday parties has to include some defining moments of parenthood for me. My daughter's birthday is in July and we've always been hopeful for fabulous weather. One year we organised a bouncy castle for the garden and a barbecue. We invited 26 children and didn't dare to imagine that the weather would be anything but sunny and warm. How wrong we were. On the morning of the party it was clear that the rain would be relentless. We had to abandon the bouncy castle and conjure up a new party at the last minute. Suddenly an army of adults emerged as expert face-painters and entertainers. We played traditional party games and had a picnic on the living room floor. Everyone had a wonderful time. When I look back I think how all the hard work that went into all our children's parties was worth every minute – every one resulting in the laughing, happy faces of lovely children.



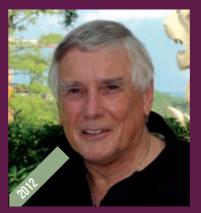


Parenthood is defined not only by the happy times, but also by the difficult times we endure. My study child was very sunny and busy when she was little; she was secure, happy, affectionate and sensitive, and I loved her cuddles. However, at sixteen she changed. She became secretive and rude, developing a hard, cold exterior and embracing 'gangsta' culture. My once-loving daughter would not tell me where she was or who she was with. She was arrested – several times and for various offences. Her behaviour became increasingly aggressive and for the past year she has been involved with a violent man. She and I do still have small windows of connection, but I've had to bar her from the house unless someone else is with me because often she is abusive towards me. The whole situation is sometimes unendurably painful – but I love her, feel responsible for her and I do endure, offering her all the love and support I can through her anger. I write this not so that others pity me, but to reach out to those parents who might also be suffering – and especially to reach out to my daughter. I hope she finds the strength to turn her life around, develop her self-esteem and become again the beautiful, loving person I know she is.

My Child of the 90s is the middle of three. Neither my first, nor my baby, he has enabled me to be a pragmatic mother to him. I have enjoyed my role as comforter, champion and guide in his life. It took me by surprise, then, that when I saw him off at his Halls of Residence, I felt an overwhelming sense of protection. I wanted to tear him from the mouldy walls and carpet, dirty mattress and broken cupboard. I had to stop myself complaining loudly about the conditions of the kitchen and bathroom. How could I leave him here? But his priorities were now different from mine – this was his adventure, to live his way. It was my turn to leave.

# BERNARD'S STORY ADVICE TO MY 21-YEAR-OLD SELF

Bernard, a study dad, turned 21 in 1967.
He was living with his parents, working for an oil company by day and at a holiday camp in his 'spare' time.
Here Bernard reflects on his hopes at 21 – and what he'd say to his younger self with the benefit of hindsight.



'Taking the opportunity to have day release from my job to go to college and gain some qualifications was one of the best decisions I made at 21 although I regret not taking the advice of my college Dean who told me I should go on to take a law degree. Instead I left college with dreams of a future that included a house in the country, a beautiful family and successful children, and the respect of my peers. I'm proud to say that I got all that in the end – but the path wasn't always easy. As I look back, if I could give my 21-year-old self some worldly advice I'd say:

- Enjoy every minute the minutes won't come again.
- Every day tell those you love that you love them they may suddenly be gone and you will never have the opportunity again.



- Don't worry about trying and failing and be prepared to take risks – trying will never hold you back, because eventually a single attempt will become a success.
- Learn something new every day – it might be about the people you meet, the world around you or even yourself ... put yourself on "receive" more often than "transmit".
- Don't wait for your ship to come in – swim out and meet it.'



four, after we had moved to Canada, we enrolled him as a Beaver Scout. He and I went on our first scout camp on a beautiful autumn weekend. We didn't know anyone: my son barely left my side for the first day. He was small, shy and quiet. Fifteen years later my wife and I drove him to the airport for a flight to Ireland and a four-month summer job. He was travelling alone, didn't know anyone in Dublin and had not sorted out his accommodation – but he was noisy, excited and selfconfident. Somewhere along the way, almost imperceptibly, our Child of the 90s had grown up and embraced his life. Now it's we who miss him.

**FULFILLING DREAMS** This year my daughter fulfilled one of my own lifelong ambitions – to visit the banks of the Mekong river in Southeast Asia. When she called me to tell me where she was, I was so proud that I had given her the self-confidence I'd never had to make the journey. In fact, she's had quite a year. She won a major fencing championship, is now travelling the world and will come back to begin her training in physiotherapy. There is no manual on how to be a good parent but, as we watch our children take their rites of passage, the rewards of parenthood become beautifully clear.

DEATH METAL IN THE HOUSE We live in Perth. Australia. My record cycling from work to home is 17.8 minutes, along the beautiful Swan river. Today I'm close to the record. As I ease my key in the door, I notice someone is retching somewhere deep in the house. I can hear the roof timbers collapsing, cracking and booming. As I make my way down the hall, the chain saws kick in. My son is a fan of progressive death metal - and when I arrive home, retching, falling timbers, and chain saws is what it sounds like. To me it's a graceless cacophony; but to him it's the purest expression of 21st-century teenage angst. Thursday is band practice. I wish I hadn't hurried home.

Nothing prepares you for parenthood; you just hope that everything you do prepares your children for their journey. When my study child was born, I did not expect, some ten years later, to become a single parent. I had to make tough decisions - including taking a full-time job. I hated not to be there at Sports Day, school plays and so on, but I supported my children all I could and tried to teach them that having a goal enables you to get on. My defining moment as a parent came in March 2012 when I watched my son graduate from the RAF. He marched to the sound of the military band – a moment frozen in my memory for ever. memories that define my experience of parenting, but I do have some favourites. Even as a two-year-old my daughter could beat me at a game of pairs – showing incredible powers of memory that have stayed with her all her life. At senior school I watched with immense pride as she played Nancy in the school's production of *Oliver!* – there wasn't a dry eye in the house as she filled the auditorium with the song 'As Long As He Needs Me'. And then there's the moment we bonded over some fatherly advice following a party at which she had overindulged, forcing us to make an 'emergency stop' on the way home.

NEW GENERATIONS To have been allowed to be present at the birth of my daughter's own daughter, to be one of the first to see my granddaughter and to be able to marvel at my daughter's composure was an utter privilege. During labour my daughter never once screamed, swore or shouted; she listened to the midwife and did exactly as she was asked. Then, as I watched her nurse her own baby for the first time, giving this tiny life the best possible start, I was overcome with emotion. At just seventeen my daughter showed such maturity – it was a day that reinforced our own bond and forged a new one with the youngest member of our family.

### THEN AND NOW

### WHAT'S IN THE WARDROBE?

From puffa jackets to neon socks, drainpipe jeans to Madonna's pointy bra, 1991 saw pure fashion freedom of expression. Over the decade jeans went from straight cut to baggy, and the hippy look made a comeback. What were they thinking?

SMILES
You might
think the 'Smiley' originated
as the icon of Acid House in
the early 1990s, but in fact this
'emoticon' dates back to the
early 1960s and a US kids' TV
show with the tagline 'Keep
Smiling'. Nevertheless, in 1991
anyone with half an eye on
fashion had a Smiley lurking
somewhere in their wardrobe.



1995 DRESSING UP
By 1995
Disney animation had given
us Aladdin, The Lion King,
Pocahontas and Toy Story. This
was a time when it was cool
to go out as a fairy – or space







At Paris Fashion Week in 2008, pundits were claiming that oversized sunglasses would be 'big for spring' – and for the springs and summers to follow it seems. With designer brands leading the way and fashion copies in every store on the high street, jumbo sunglasses have, in recent years, brought instant glamour to summer fashion.

SKINNIES

If 1991 was a year for drainpipe jeans, then 2012 is the year of the skinnies. Worn with ballet pumps, US-style 'sneakers', boots or wedges, and in colours from jet black to

aqua green and bright red,

essential of this year.

skinny jeans are the wardrobe

# TWENTY ONE... MOMENTS THAT HAVE CHANGED YOUR LIFE

From overcoming illness and bereavement through raising money for charity and triumphing at sports, to (almost) becoming a rock star, your life-changing moments are inspirational, thought-provoking and full of hope. Over the following pages young people and parents reveal 21 memories that in small ways and big ways have defined their lives.

From you, our young people:

I practise Dragon Tang Soo Do, a Korean karate. In March 2012 I completed my first Dan black belt grading. Many people go through this, but for me it was a bigger deal than anyone else realises. I had been told by doctors that injuries to my shoulder and knee meant I shouldn't continue with the discipline. But I wasn't to be beaten and I battled through. I gained my belt and with it came respect from my club. I am now assistant instructor and I have competed in some major competitions, walking away with first-place trophies in both the InterClub and the Open Championships. Sometimes moments that you think might change your life in negative ways, in the end spur you on for the better.

PART OF SOMETHING Sitting in a Focus visit, aged fifteen or sixteen, changed my life. In that moment I realised that the project I was part of – and had been a part of since before I was born, that seemed second nature to me – was making a real, tangible difference to the world. After that visit I would get so excited every time I read about Children of the 90s research. I believe that being part of the study has given me my love of science, particularly of biology – which is now the focus of my university study. I hope that one day I'll not only be able to provide information as a Child of the 90s, but that I can be at the analytical end of the results, making scientific research my career too.



RACE FOR LIFE Someone recently wrote to me about a girl who on Christmas Day would walk the streets of her city and feed the poor, sitting down and having a conversation with them. As a result, I think May 2012 changed not my life, necessarily, but certainly my mind. I ran Race For Life for the first time. I'm not athletic, but I understand now that it takes dedication to raise awareness and force change. I realise that we all need to be a little less selfish. Sometimes it isn't a big thing that changes your life; instead you can change many lives simply by changing your attitude.

LEAPING FOR LIFE I had meningitis when I was five months old. Doctors told my parents that I had only an hour left to live, but miraculously I pulled through - not only surviving, but without any side effects at all. Knowing how close I came to death and how others often pull through but with devastating results, from chronic pain and memory loss to complete paralysis, has helped me appreciate just how lucky I am to be here to live life to the full. In April 2011 I took part in a sponsored skydive from 12,000 ft and I managed to raise just over £350 for a meningitis charity. I dedicated my dive to the fantastic doctors who helped save my life. Thank you.

ANIMAL RESCUE A trip to Edinburgh Zoo on my twentieth birthday changed my life. Ever heard of sun bears? Me neither until that day. The smallest members of the bear family, they come from southern Asia. While I was watching Edinburgh's two sun bears playing together, a zoo keeper told me they had been rescued from cages far too small for them in Cambodia, where they are hunted illegally. In that moment I decided to campaign for their cause. Since my trip to the zoo, I have blogged and raised money to help save the bears. One day, when I've finished university, I hope to travel to Cambodia to work in a bear sanctuary and help these animals first hand.

CYCLE OF LIFE My life changed when I was crumpled on the floor of a drafty crematorium on the day of my flatmate's funeral. He died unnecessarily. Sitting there, I realised I was pregnant: new life in exchange for death. Someone, I can't remember who - a film of tears coated the entire day had hold of my arm. I cried. I cried for the loss of my friend; for the cruelty of life. I cried because my baby would one day experience anguish and pain like this. As they played songs I'll never listen to again, I got up to pay my respects. He had his mother's eyes; his father's build – fragments of him left over. 'It's freezing up North,' I said. His father laughed and shook my hand.

LIFE AFTER MUM

If you walked past me in the street, you would have no idea how completely my life changed in 2007. Every day I'm sad that my mother is dead. I saw how her cancer made her suffer and I watched as she fought to hold on for her loved ones. In the moment she died my family became so fragile. Her death affects every part of my life, but as I begin to cope I can learn from her strength, courage, perseverance and love. It warms my heart to keep her spirit alive. Although I now go to Focus visits alone, I'm proud to continue with the project my mum joined. I feel stronger and more resilient. I take more time to appreciate the people in my life and I am closer to my dad. I have grown up beyond my years; I laugh to myself when people say, 'This is the worst thing in the world.' My younger self would have thought it incomprehensible that I would make my journey beyond 21 without my mum. But I am beginning to see now that it will be okay – my life after mum.

WILL AND WELLNESS

What makes a moment? Mine was three months in 2008; a vacuum of motion as I suffered the effects of Guillain-Barré Syndrome – neuropathic bad luck that saw my nervous system destroy itself. With no cure other than the body's own will to fight, I spent summer in a state of paralysis. My recovery was one of the fastest and fullest seen or heard of. Why? Perhaps it was the juvenile oncology ward I lived on, where children faced their mutinous bodies without the distraction of paralysis. Perhaps it was knowledge: anatomical interest from being part of this study. Perhaps it was the little window that I bargained for, a glass canvas painted with colours of Totterdown houses, as the city I love so much sat beyond my reach. Whatever it was, I got out, a better person than ever before – and that is thanks to the moment I realised that life was infinitely too precious to ever justify wasting.

TURNING LIFE AROUND

As a young child I admit I could be really nasty and unkind. I didn't pay attention in school, or take life seriously. Then, in September 2003 I went to secondary school. There I found I could be more independent, I could be smarter and I should take things more slowly - there was no benefit to rushing. After secondary school life just got better and in March 2009 I won an Achiever Student award, and I was the runner up in another category. I felt really good about myself; I felt happy. In that moment I realised that there was a lot I could achieve if I put my mind to it. Now I'm at college doing Media Studies and looking forward to a better future.



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FROM THE ALBUM

### WHERE ARE YOU NOW?

Although Children of the 90s originated in the old county of Avon, we couldn't, of course, expect that you would always remain on our doorstep. In fact, at the last count, 523 of you had scattered across the globe. Happily, distance doesn't seem to have deterred your enthusiasm for being part of this special study. Take a look at the list below to see all the places that some of you now call home.

Australia	112	Germany	17	New Zealand	33
Belgium	10	Ghana	2	Nigeria	2
Brazil	1	Hong Kong	- 5	Norway	2
Canada	37	India	5	Portugal	4
Channel Islands	17	Ireland	64	Qatar	1.75
Cyprus	6	Isle of Man	6	South Africa	7
Denmark	4	Italy	3	Spain	32
Ethiopia	2	Lebanon	2	Switzerland	10
France	36	Luxembourg	1	Thailand	3
a and draw a second		Malaysia	2	United Arab	9
		Mauritius	2	Emirates	
		The Netherland	ls 10	USA	70
		New Caledonia	11	Zimbabwe	1
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Sometimes events that might seem small for some can have life-changing effects on others. I think one of my lifechanging moments was moving away from Bristol. Although many at age seven would simply take such an event in their stride, I remember having mixed feelings about it. I was upset and scared (especially about leaving my friends), but also excited and pleased to be going closer to family. It was hard settling into a new school and making new friends, but as I think back on it I realise how lucky I've been. If I hadn't moved I wouldn't have met the amazing people I now count among my best friends - and I wouldn't know their children. I love them all.



**RUGBY FIRST** In September 2010 I started playing senior rugby for my club. At seventeen years old I was the youngest player on the pitch and it was the first match I'd played with my dad. He was in centre; I was on the wing and we played Kingswood RFC. My opposite number was a similar age and size to me, but wasn't as strong or as fast. My dad kicked the ball forward, and my opponent and I both chased it. I won it from him and charged for the try line, crashing through Kingswood's fullback to score my first senior try.

# JENNY'S STORY WHERE I LIVE NOW

When Jenny was six years old, she and her family moved from Bristol to Scotland, but that wasn't the end of their journey. In July 2008 she and her mum, dad and two brothers relocated again, this time across the Atlantic to Pleasanton in California, USA.





'My dad works for a US company and in 2008 a promotion meant he was asked to relocate to California. At first we thought it would be for only two or three years and we kept our family home in Dunblane, Scotland, with the intention that we'd go back someday. However, the Glasgow branch of the firm closed down and it made sense to stay in the USA.

I miss aspects of the UK – the chocolate, the British sense of humour, and our family and friends, of course – but America has lots of wonderful things going for it. I love that we can afford to ski and eat out; I love the climate (I've almost forgotten what rain looks like) and the fact that students seem

to have more opportunity to play sports and study music.

No matter where I live, I shall always be part of Children of the 90s. I love filling out the questionnaires and reading the newsletters. Being able to keep in touch online is fantastic.

I'll be back in the UK soon to begin my nursing degree at Glasgow University, but once I've finished, I'll come back to the USA. Although living abroad was daunting to start with – I "hated" it for the first six months and was very homesick – within a year I'd found the inner strength I needed to make new friends and to enjoy High School. Now the USA (pictured, far left) is my home.'

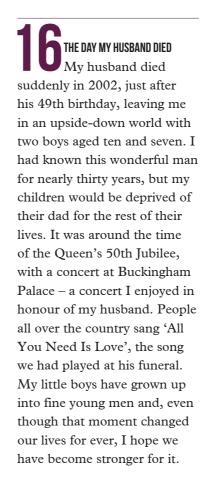
From your parents:

My eldest child is 22; my study child is twenty; my voungest is at secondary school. Faced with an emptying house and a 'baby' who needed me less, I had to fill the gap. I had always wanted to write, so I did an Open University creative writing course, then I did another. Then I spent a year writing my first novel. The first day that changed my life was when an agent called to say he loved my book. The second was the day he got me a threebook deal. I published my first book in 2011; my second, in spring 2012; and I am just finishing the third. I have found what I want to do when I grow up. Empty nest sorted.



In the ante-natal clinic at St Michael's Hospital, Bristol, in April 1992, eighteen weeks into my second pregnancy, the ultrasound nurse suddenly said, 'Oh there's another head down there.' I was expecting twins. My husband went white. When they were born my twin boys were a near-record weight, at 8lb and 8lb 3oz. People whispered about them all over the ward. Now students aged almost twenty, they have never missed a Children of the 90s session. My twins changed all our lives, and I am so proud of them and their wonderful sister. Despite the hard work of the first few years, I wouldn't change a thing... except perhaps my bad back.

in New York - and were there when two aeroplanes hit the Twin Towers. I was amazed by how calm my ten-year-old was about it; her three-year-old brother, though, spent six months or so repeatedly drawing pictures of planes flying into sky-scrapers. Their school had managed to protect the children from what had happened until the end of the school day, by which time I knew my partner was okay. On the following Friday we were standing outside a restaurant, watching the smoke as it still rose from downtown. The children were emotional - each of us holding a candle; each of us aware how lucky we were to be a family intact.



Was it there when she was born or did it start growing when she was learning to walk, or on her first day at school, or when she was learning to swim, or during any one of the hundreds of other typical growing-up milestones? This was not a typical milestone nor one that any parent would ever choose. 'Your daughter has cancer' – four quiet words that we heard on an otherwise regular kind of day. Unbelievable, not happening to us, there must be a mistake, surely not and on and on... . And then the questions: how, what, when (especially when) and of course why? When did the cancer start to grow and why now at nineteen – just as she is about to set off on her own journey into the world? A life-changing moment captured in four words: from familiar, safe and ordinary, to complicated, frightening and unknown. But also a new way, one of hope, determination and resilience – and of recognition that we



should never take life's journey for granted.

THREE GIFTS

'We are going to the beach tomorrow. I can't wait, I am dying for a swim...' She died the next day while swimming in the sea at Glenelg in Adelaide, Australia – the most tragic and desperate time of my life, but through her death she gave me three gifts.

Before she left she told me, 'I do not really like flying. I'm not brave, though, it's just I am not afraid of dying – it's a win–win situation. I get to take some risks and have fun all at the same time.'

This was her first gift. I have since travelled to wonderful places, and taken life less seriously and pleasure in simply being alive.

When I was sorting through her personal effects, I noticed how many anti-ageing products she had bought, but at 63 she had never really grown old. I decided that worrying about ageing was a waste of energy.

This was her second gift. I love my wrinkles; they show the world how full of laughter my life has been.

Mum emailed me from Australia to tell me all about her holiday. I was busy and intended to reply the following day, send her a kiss and tell her 'I love you.' But she died and I never sent her a kiss or told her that I loved her.

This was her third gift. From that moment I have never waited to tell someone they are loved and special. I tell them there and then, and I make the time for the really important things in my life.

Thanks Mum.
PS I love you X

day in June and I had plenty of time to walk to the surgery for my ante-natal check-up. The young doctor couldn't find a heartbeat. Moments later, calm, but serious, the senior partner told me I should go to hospital for a scan. There, a junior doctor couldn't look me in the eye when he told me he thought my baby may have died. She was born the following morning – still-born, weighing less than 11b. When Professor Golding invited me into the study during my next pregnancy, I immediately agreed. I knew that her work might help others prevent such sad outcomes.

My life changed in the year I was pregnant with my third child, my Children of the 90s son. Having noticed some night blindness, I was diagnosed with retinitis pigmentosa, a genetic disease that leads to blindness. After the initial shock I got on with bringing up my four kids. Now my son is 21 and studying optical engineering at college. I'm adjusting to using a cane and learning to function in a non-visual world. My family and I have learned so much about overcoming obstacles – often literally – finding the positive in even the bleakest situations. I am so grateful I could see as my beautiful children grew up and I'm positive about the future.

In the winter of 1981, I was on an ill-fated tour of the western USA with a pop group. If the recent assassination of John Lennon hadn't been enough to deflate my rock-'n'-roll spirits, then events on this tour certainly were. The band had split acrimoniously and two of us, by some miracle, had managed to drive back the thousand-or-so miles to LA in an unroadworthy vehicle, with no money and in fear of pursuit by our insidious, control-freak lead vocalist. By then I'd been involved in the music business for four or five years, firmly believing that my talent alone would lead me to inevitable rock-stardom. However, with the break-up of the band, I gave up music altogether, flew back to the UK and began training as a computer programmer. I decided the only way forward was through study and self-discipline. It wasn't long before I returned to music, of course – within a year – but since then I've approached it with a new work ethos. Talent is all very well, but any degree of success as a musician, music teacher – or anything else – needs commitment and sheer hard work.



### THEN AND NOW

### WHAT'S IN THE TOY BOX?

As you download the 'retro' game of Sonic the Hedgehog for your smartphone, you might like to know that it was 1991 when Sega launched the original Sonic for their Sega Megadrive console. They issued the GameGear handheld console that year too.

SUPER MARIO
As Sega was launching its most famous games in 1991, Nintendo was already soaring, winning a best game award for Super Mario World in which Mario, Luigi and the dinosaur Yoshi set out to save Dinosaur Land from



1991—2012 LEGO KEEPS BUILDING
One of the most enduring toys of our times is LEGO®. In 1991 LEGO launched the Nautica collection of sea vessels, and since then has given us everything from Winnie the Pooh to Star Wars and, of course, Harry Potter. In 2012 LEGO launched its Ninjago range of Ninja warriors for its newest fans.



By 1996 Barbie was already almost forty years old, although she didn't look it. While you may have had Barbie at home, Polly Pocket made the perfect travelling companion. Also by the mid-90s 'Troll Dolls' had a surge in popularity, with even a video show of their own.

# 2003 NINJA TURTLES RISE AGAIN

Following their huge success in the late 1980s and then launch as a Gameboy Advance game in 1990, Teenage Mutant
Ninja Turtles – Michaelangelo,
Donatello, Leonardo and
Raphael – rose again as a new animated TV series in 2003, which was accompanied by a new video game for the PlayStation 2, Xbox,
GameCube and Windows PC.

# 2012 FROM CONSOLE TO ONLINE GAMES

Do you remember having to be attached to your TV as you played games on it? Now, of course, we can play by simply waving our hands or a remote – and our opponents don't even have to be in the same room. In modern gaming we can play against those we know and those we don't through the magic of the World Wide Web.





### PART TWO: JOURNEYS OF DISCOVERY

# YOUR CONTRIBUTION TO SCIENCE AND SOCIETY

# Whether gathered via questionnaire or Focus visit, your information has been collated and filed, and much of it has been analysed. We've used your data to conduct our own research into factors influencing health and development, and researchers all over the world have had the opportunity to do the same. In this section you'll find discoveries that have resulted from your commitment to Children of the 90s. Some of them you may already know about, others you may never have imagined possible. From insights that protect our well-being to 'eureka' moments that deepen scientists' understanding of the nature of disease, this chapter is a treasure trove of scientific gems.

# TWENTY ONE... NUGGETS OF PRACTICAL WISDOM

### We use the information you give us to find out

how we can make life not only safer and healthier, but more fulfilling too. Whether it's advice to safeguard an unborn child, or about the benefits of exercise or the dangers of drugs or alcohol, Children of the 90s research has given the world a wealth of practical wisdom that millions of people now put into practice every day.

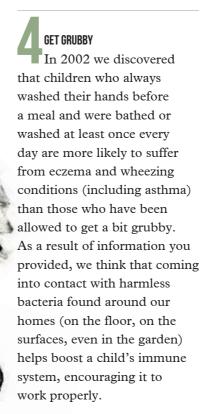
RAISE A CUP
Toddlers encouraged to drink from a cup rather than a bottle are more likely to develop a healthy, varied diet than children still drinking milk from a bottle at eighteen months, which may make them less likely to want other kinds of foods. However, don't put fizzy drinks or squashes in the cup. Drinks with no nutritional value may be detrimental to children's diet and their teeth.

No Cannabis during pregnancy
It has been common knowledge for a while that smoking tobacco during pregnancy can result in a smaller ('low birthweight') baby, but Children of the 90s research has revealed that cannabis also has that effect. The results stack up even if we account for the fact that cannabis smokers tend to be younger and smoke tobacco too.



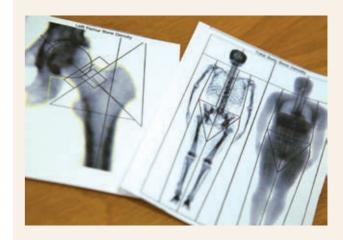
In 2007 US guidelines recommended that pregnant women limit their intake of oily fish – but we beg to differ.

Our study shows that eating oily fish – which includes fish such as mackerel, sardines and salmon – during pregnancy may improve the development of sight, IQ and positive social behaviour in children.



BUILD STRONG BONES

Eating healthily from a young age is essential for helping our children's bodies to build strong bones. In 2003 we published our analysis of 757 of your diets, which we related to the strength of your bones (your bone density). Perhaps you remember having a bone density scan when you were nine? By comparing the results from the scans with your diet at age eighteen months, we have confirmed that those of you with more varied diets (probably similar in structure to the diets your parents were eating at the time) have stronger bones. 'Banking' strong bone during childhood and adolescence is important for preventing breakages during old age, when bones inevitably become weaker and more brittle. A good reason why children should eat a well-balanced diet.





46 JOURNEYS OF DISCOVERY

TWENTY ONE NUGGETS OF PRACTICAL WISDOM 47



GET ACTIVE Between 2003 and 2005 we asked 5,500 of you to wear a special 'accelerometer' belt to measure the amount of physical exercise you did every day for seven days in a row. We showed that children who do more physical activity every day (even simply walking to school) have lower blood pressure and may be less likely to develop heart disease in later life. We also discovered that only 2.5 percent of you did around sixty minutes of physical activity a day – boys did more than girls. Even just fifteen minutes of daily vigorous exercise can reduce obesity risk by half.

### BREAST IS BEST

Some Children of the 90s findings have become common knowledge to the extent that we simply take them for granted – 'breast is best' is one of them. In 2007 we announced that data you have given us show that babies who are breastfed are generally better able to regulate what they eat as they get older – and as a result tend to be less likely to become overweight or obese. Another study that used data from Children of the

90s found that breastfeeding may help to raise the baby's IQ in later life – and this finding has been supported by similar discoveries in another birth cohort study in Brazil. Thanks to you we have further evidence to encourage new mums to breastfeed if they want to and are able to.



GOOD FAT, BAD FAT
When you were fifteen
we analysed your bone shape

and bone density, as well as the amount of body fat you have. We discovered that teenagers with more body fat tend also to have larger, denser bones. In other words, their bones were stronger. However, we have also discovered that high body fat can cause problems for your health, including worse risk factors for heart disease and obesity. The important message, then, is that while higher body fat can help build strong bones,

the risks outweigh the benefits.

### MONITOR MILK

Did you know that calcium (in cows' milk) hampers the body's ability to absorb iron from food? We need iron so that our body can make red blood cells. When we don't have enough red blood cells, we're said to be anaemic. We have shown that children who are given cows' milk before twelve months of age are more likely to develop anaemia, while those who are still breastfed as their primary source of nutrition (which means they have more than six breastfeeds a day) after eight months also tend to be iron deficient. The message is clear: try to keep your baby's milk feeds to fewer than six a day, make them breast or formula milk rather than cows' milk, and make sure that the baby's first solid foods contain (in suitable

form) lots of iron – which is found in meat, pulses, fortified breakfast cereals and green leafy vegetables, such as spinach.







TV-watching habits of 9,629 of you to see what impact TV might have on your language skills and your performance at school. We found that those of you whose parents interacted more with you when you were very young – by reading books, playing games and simply talking to you, and who restricted the amount of TV vou watched - had an early advantage when you first went to school. The better you were able to talk before the age of two, the greater your head start. This research has been included in the Nutbrown Report, an independent report into early childhood learning commissioned by the Government.

We have shown that babies who are weaned on home-cooked vegetables are much more likely to go on to eat the recommended 'five-a-day' as toddlers and young children. We studied food diaries kept by your parents when you were introduced to solid foods and found that if you were given home-prepared food at six months old, you were more likely to eat more fruit and veg when you were a toddler than children who'd been fed ready-prepared foods. We aren't yet sure why - it might be that ready-prepared foods taste much more bland and so babies who eat more of these don't give their tastebuds the opportunity to experience and get used to 'real' flavours and textures. Or it might be that babies weaned on readyprepared foods come from families who generally don't eat many fresh fruit and vegetables. Either way, we now know that weaning on home-cooked foods is good for a baby's long-term diet, and so is good for health.



We looked at how much lead 500 of you had in your blood when you were two years and eight months old and compared that with your SATs results at age seven. We found that higher levels of lead in your blood had a negative effect on how well you did at school. At high levels it may also lead to hyperactivity or antisocial behaviour. Lead can get into our bodies from drinking water, from the air, or from food grown in leadrich soil. Our researchers recommend that we wash garden toys to remove the lead they may pick up from the soil, wash fruit and vegetables before we eat them, and let the cold water run for a bit before filling up a glass to drink.

At Children of the 90s we wanted to see what effects having a working mum might have on your development. In May 2003 we revealed that, at the age of three, those of you who spent time in childcare were as emotionally well-developed and as active as those of you who spent all day at home with your mum. It seems that working mums forego their own personal time so that when they aren't working they make an extra effort to stimulate, talk to and play with their babies and toddlers.

That's great news for working mums – but families do need to be careful about what kind of childcare they use. In August 2003 we showed that the type of childcare you had affected your intelligence. We discovered – looking at the data of 12,000 of you – that those of you who were looked after only by a member of your family or by a friend before you were eighteen months old (with your mum back at work full time) didn't develop quite as quickly as those of you who were looked after by your parents or who went into formal daycare. Overall, though, the differences were small and, happily, if your mum worked, your dad seemed to be much more involved in interacting with you. This is another piece of great news – because we have also shown that dad time is important for both the physical and intellectual development of children.

GO BACK TO SLEEP In 1991 the UK Government launched its 'Back to Sleep' campaign to encourage new parents to put their babies on their backs to go to sleep, claiming this would reduce the incidence of cot death. 'Back to Sleep' is now accepted wisdom - in part thanks to you. In 1992 we gathered data from you that subsequently showed that there are no major health risks involved with putting a baby to sleep on his or her back, whereas cough and fever were two of several health risks of sleeping on the front. In 1998 we also showed that there were no long-term implications for a baby's motor skills and mental development as a result of sleeping on his or her back.

DON'T PASS THE SALT TO BABY The stage at which a baby starts on solid foods (weaning) marks a critical time in his or her development. For example, it can influence whether a child chooses to eat healthy or unhealthy foods well into the future. In 2012 we published evidence that at eight months old more than seventy percent of you were eating over the Government's recommended sodium (salt) intake for babies under one year. As a result, we know that baby-food manufacturers may need to mark the sodium content of their foods more clearly so that new parents can keep their baby's intake as low as possible.

Part of Government strategy to help reverse the trend for childhood obesity is to encourage children to become more physically active. One simple way to do this is to walk to school. In 2009 we analysed data taken when you were eleven years old about how often you walked or cycled to school, how often vou travelled there in a car and how far you had to travel. Those of you who lived more than half a mile away from school showed an overall increase in the amount of moderate to vigorous exercise you did during any given week compared with those who lived less than half a mile away, and of course those who travelled by car.

# TOM'S STORY FRIENDS IN FOCUS

It has always been really important to us that you all feel as happy as possible when you come for Focus visits. Here, Tom reflects on his memories of some Children of the 90s staff.

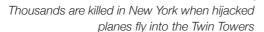


of the 90s since the day I was born. I didn't go straight home from hospital and my first contact with study staff was while I was in the special care baby unit at St Michael's in Bristol. While I was there Hazel met me for the first time and looked out for me. I began coming to "Children in Focus" visits when I was about three years old. I was painfully shy and my mum used to keep where we were going a secret, as otherwise I wouldn't go with her. However, Hazel was always there when I arrived and she and I built up a strong relationship. She began to mean a lot to me and she helped me realise how much the study itself meant to me too. By the time I was nine or ten years old, I couldn't wait for my next Focus visit – I used to love it when the appointment letters arrived and I was being called in. And it's not just Hazel who has made an impression on me.

'I have been part of Children



Nicki and Susy also deserve a special mention – as do all the members of staff at the Focus centre. It is completely true to say they have always been so friendly and so caring. It's thanks to them that Children of the 90s has been such an amazing and enjoyable thing for me to be part of. I shall continue to contribute to the study for as long as I can, so that I can help children and families in the future. I want to thank the incredibly dedicated and hardworking team behind the scenes.'





JUNK THE JUNK We know that junk food leads to an unhealthy body, but 4,000 of you have shown us that it also affects your brain. Your parents filled in questionnaires when you were three, four, seven and  $8\frac{1}{2}$  to tell us what you ate and drank. At 81/2 we measured your IQ and we compared what we know about your diet with your intelligence scores. We discovered that if you had had a 'health conscious' diet (including fresh fruit, salad, fish, rice and pasta) before the age of three, you were likely to score much higher in the intelligence test than those who had been raised on a 'processed' (junk food) diet.

In 2009 we published a ground-breaking study that identified eight circumstances under which the under-threes are more likely to suffer obesity in later life. Some of these eight 'risk factors' are beyond our control – such as a child's 'adiposity rebound', which is the age at which baby fat disappears and the child becomes naturally leaner and thinner (before potentially gaining fat again). If your adiposity rebound happened before you were 3½, you are more prone to obesity. Other risk factors, however, are within our control, including watching less television (more than eight hours a week by age three is associated with increased obesity risk) and ensuring our children get enough sleep. Children under the age of three who get fewer than  $10\frac{1}{2}$  hours sleep every night are more likely to suffer from childhood obesity. There are many reasons why this may be the case. It could be because the length of the nighttime sleep may affect growth-hormone secretion or because sleep reduces a child's exposure to other factors that promote obesity, such as eating in the evening. Alternatively, how long a child sleeps at night may simply be down to how physically

active they are during the day.

In 2009 we revealed that pregnant women who drank more than four units of alcohol on a single day, even if they were otherwise light drinkers or didn't drink at all, put their babies at risk of developing attention-deficit disorders or other mentalhealth problems by the time the children reached between four and seven years old. Interestingly, girls showed signs of hyperactivity or attention deficit disorders at an earlier age than boys although both were equally at risk by seven.

When you were only four weeks old, amazingly more than 12,000 parents told us what was going on in your nappy. A quarter of you were having trouble with nappy rash - and we wanted to find out what was causing it. We concluded that if you were very poorly or if your parents introduced cereals (such as baby rice) to your diet very early, you were more likely to get nappy rash. We also found that using disposable nappies did not prevent nappy rash. As a result, hospitals and midwives encourage new mums to try washable cotton nappies, which do not contain harmful chemicals and are kinder to a baby's skin.

KEEP SWIMMING Pregnant women often ask their midwives if it's safe for them to swim or whether the chemicals in the water might harm their unborn child. In 2002 we looked at data given to us by more than 11,000 mums during their pregnancies. The information led us to conclude that neither the 'organic matter' (such as skin and hair) in swimming pools, nor the chemicals (such as chlorine) used to keep the water clean posed any serious threat to the unborn child. In fact, the health benefits of being active during pregnancy appear to make swimming the perfect exercise.



# THEN AND NOW WHAT'S ON THE PLAYLIST?

**Blur, Oasis, Take That, EMF, Ace of Base** – your parents will wax lyrical about the songs that remind them of life when you were born. The early 90s gave us Britpop at its best, as well as boybands – and girlbands – that have stood the test of time.

1991 BRITPOP In 199

Blur released their debut album Leisure and Britpop had truly hit the music scene. Along with bands such as Lush and Suede, Blur were soon joined by the Gallagher brothers' Oasis and by the mid-1990s the 'Battle of Britpop' was underway. The high point was the release on the same day of Blur's 'Country House' and Oasis's 'Roll With It'. Blur took the number-one spot, forcing Oasis to settle for that week's number two.

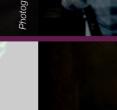
1994 POP POWER Sporty, Baby

Scary, Posh and Ginger – the Spice Girls first sang out in 1994. By 1997 manager Simon Fuller had given us SClub7 too; and Tim Byrne had created Steps. Remember the moves for 'Tragedy'?



1994 TRIP HOP In 1991

Bristol-based Massive Attack pioneered trip-hop music, a melancholy electronic sound that reached its peak in popularity in 1994–5, with albums by Tricky (once of Massive Attack) and Portishead. In 1997 Roni Size, a Bristol-born DJ, kept the city firmly at the heart of the music scene with his drum-and-bass act Reprazent.







2005 ANTHEM SOUNDS
By the
new millennium Britpop and
trip-hop had given way to the
more anthemic and gentle
rock sounds of bands such as
Coldplay – their album X&Y
was the best-selling rock album
of 2005. Also in 2005 Arctic
Monkeys helped revolutionise
how we buy music, releasing
their single/EP 'Five Minutes
with Arctic Monkeys' primarily
as an Internet download. In
2007 Radiohead went a step
further, letting fans choose

how much to pay to download

their album In Rainbows.

2012 ALL DIRECTIONS

music is characterised by its diversity. While some swoon over boybands such as One Direction, others celebrate Bristol's 'dubstep' scene. Meanwhile, the haunting sounds of Adele and dance tracks from Rihanna provide something for everyone.



Laid Blak at BrisFest 2011

# TWENTY ONE... KEY DISCOVERIES THAT IMPROVE OUR LIVES

So much of what you've taught us has had a tangible effect on policy and procedure in all walks of life – from the labels on packaging to the advice given to pregnant women. The following are 21 of the key discoveries that have already had an impact on the way we live and are cared for today.

**BREASTFEEDING AT WORK** We've shown that if your mums intended to return to work before you were six weeks old, they were less likely to begin breastfeeding than mums who had no return-to-work plans. Given the benefits to a baby of breastfeeding, we highlighted the importance of employers providing adequate facilities and supporting flexible working patterns so that women who return to work shortly after the birth can continue to breastfeed.

LAZY EYE SCREENING In 2002 we showed that if you had amblyopia – or 'lazy eye' – screening regularly up to age three, as opposed to a single assessment at three, resulted in earlier correction. However, we have also shown that attendance at early checks is low, leading to recommendations that vision should be checked as early as possible once good attendance can be guaranteed – and that is at school entry. This is now the guideline of the National Screening Committee.



PEANUT OIL ON PACKAGING The Ministry for Agriculture asked us to investigate how peanut allergies develop. We found that those of you who suffer from eczema are more likely to develop a peanut allergy, so there must be a link. And there is. If your parents used skin creams containing peanut oil to soothe your skin, you were more likely to go on to develop the allergy. We think that tiny traces of peanut oil enter through the skin, sensitising the body to peanuts. As a result, all skin creams now list their ingredients and state clearly whether or not they contain peanut oil.

DON'T SHOUT We love making 'firsts' in scientific research. One of our firsts is our investigation into the causes of voice disorders, known as dysphonia, which give children a breathless or harsh-sounding voice. In a sample of more than 7,000 of you, we discovered that the most likely cause for developing dysphonia when you were eight years old was having older brothers or sisters (siblings). And the more siblings you had, the more likely you were to be affected. We found that it was more common in boys than girls, as well as those with asthma or hearing loss and those who suffered from chest infections.

Thanks to your data, we've been able to reinforce the importance of checking a baby's weight regularly. When you were babies we carefully recorded your weight at birth and you had your weight checked by your health visitor several times. We plotted these weights on a 'growth centile' graph, a chart that showed us how you were growing relative to established 'norms'. Those of you who grew more slowly compared to the 'norms' were said to be 'slow weight gainers' and we wanted to see how that might affect your later development as you grew up. We found that 'slow weight gainers' had more difficulty with feeding and needed more support during this phase. By eight years of age, those of you who had been 'slow weight gainers' had almost caught up in weight and height and were likely to grow to a height similar to your parents.



ECZEMA GENE We've long suspected that eczema has a strong genetic influence – that is, something you've inherited from your parents makes you more likely to develop eczema and other allergic conditions. We've identified that if you have a particular genetic variant of the 'filaggrin' (FLG) gene, you're more at risk of eczema, and less likely to grow out of it quickly. Now that doctors know about this gene, they can identify those who are most at risk and try to develop treatments to stop the development of eczema in those children. We also discovered that eczema itself might trigger other conditions, such as asthma. (For more on eczema, see page 66, too.)

In 2005 Jamie Oliver launched his campaign to improve the lunches schools provide for their pupils – but we have discovered that so-called 'school dinners' are only part of the problem. In 2007 we assessed the three-day food records of 621 of you when you were seven years old. We wanted to see what differences we could find between the school lunches your schools provided and the packed lunches that your parents or carer had made for you at home. We discovered that the hot lunches provided by your schools lacked vital nutrients. They included too few vegetables and fruit and were too high in saturated ('bad') fat. However, we also found that your packed lunches were, if anything, more unhealthy. The food you brought from home not only had even higher levels of saturated fat, but also of sugar. They also had lower levels of potassium (essential for the health of your heart, brain and other organs) and zinc (good for your cells and immunity). Your school lunches were giving you more protein, fibre and starch than your lunchboxes. Thanks to you we know that it's not just what happens in the school kitchens that needs to change, but in the kitchens at home too. Our research has been used 34 times in an attempt to get this important message out there.

RESUSCITATION AND IO

Birth is an amazing thing – but can be traumatic for both mother and child. Remarkably, given the risky nature of a newborn's journey into the world, only a very small percentage of you needed to be given oxygen to make you breathe immediately after you were born. We wanted to find out if there was a link between your intelligence score when you were older and the fact that you'd had to be resuscitated at birth, even if you showed no signs of any side effects of the treatment as you grew up. More than 5,500 of you completed an intelligence test when you were between eight and nine years old. Looking at those answers, we were able to work out that, even if you were perfectly healthy after you'd been resuscitated, there was a strong possibility that it could affect your IQ test in later life. This suggests that, even though differences can't be seen straightaway, having to be brought back to life might affect your future learning power.

### INFANT SLEEP AND CHILDHOOD **BEHAVIOUR**

In 2012 we published research that identified that those of you who had 'sleepdisordered breathing' when you were infants were up to fifty percent more likely to become hyperactive by the time you were seven years old. Sleep-disordered breathing includes snoring, noisy breathing during sleep, and sleep apnoea (a condition where you momentarily stop breathing as you sleep). This link could help doctors understand the importance of treating such sleep conditions before a child reaches one year old – not only to ensure healthy physical development, but to encourage healthy emotional development too.



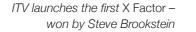
### MOTHERS' SMOKING AND CHILDHOOD BEHAVIOUR The links between smoking during pregnancy and babies being born with a low birthweight are well accepted. However, until we looked into it, less well known was the link between mums who smoke while pregnant and their child's behaviour in later life. We compared your results with those from another, similar, study happening at the same time in Brazil and found that regardless of age, background or social status, if your mum smoked, you were more likely to 'externalise' your problems - that is, you may have shown signs of antisocial behaviour, found it difficult to form good relationships with people your own age, or suffered from hyperactivity disorders. We found that the chances of you having emotional issues, or internalising your problems (in other words, keeping them locked inside, rather than talking about them), were no different from children born to mums who did not smoke during pregnancy.

Is giving up smoking during pregnancy a simple matter of will power? We've discovered that the answer is no. Some women carry a gene that makes it especially hard for them to give up – the same gene that also makes them prone to 'heavy' smoking before and after pregnancy. More than 7,000 of your mums showed us that there's a link between genes and quitting. Now we know that smoking mums may need additional support to find extra reserves of will power so that they can overcome the genetic make-up that actually makes it harder for them to quit.

■ We asked some of your mums to fill in a 'food frequency questionnaire' when they were 32 weeks pregnant - this told us how often they ate from 43 different food groups. When you were ten we asked you and your carer to record anything you ate and drank for three days. We discovered that if your mum ate healthily when she was expecting you, you were more likely to prefer healthy foods at age ten – and vice versa. This tells us that healthy eating during pregnancy is important not only for the development of the unborn child, but also because what a mother eats may programme the baby's dietary habits into the future.

Your teeth tell us a lot about your health. Children of the 90s and a similar study in Finland compared the dates of tooth 'eruption' (when your first tooth came through) and the number of teeth you had at age fifteen months to genetic information. The same genes were found to be important in each of the studies. These were genes that others have shown to be linked to dental problems in later life. Some of the genes that were identified also have links with cancer. Rather than being cause for alarm, these discoveries have become essential to our study of the development of chronic diseases – cancer being one.

In 2010 we looked closely for a link between your genes and your susceptibility to low lung function. This is associated with a lung disorder in adults known as chronic obstructive pulmonary disease (COPD), which makes breathing increasingly difficult. We established that a link does exist and the same genes are associated with COPD in adults. Importantly, this association exists whether or not vou are a smoker. Soon doctors may be able to study patients' genes to identify those more susceptible to COPD and encourage those people to take steps to minimise the chances of developing the condition, or to minimise its effects.



One of the most important aspects of our study is to highlight where society favours or under-supports certain groups of people. We asked your mums eight weeks before and eight weeks after you were born whether they had experienced backache or depression or had had a urinary infection. Broadly speaking we found that those from poorer backgrounds reported more psychological illnesses, such as anxiety and depression, while mums from wealthier backgrounds went to the doctor with physical ailments. The results suggest that more needs to be done to support the mental well-being of mums in all walks of life to ensure that all women feel properly cared for.

DEPTH PERCEPTION 'Stereoacuity' is the ability to perceive depth seeing in 3D, if you like. Babies are born with very little depth perception, and it's not until they reach around five years old that they can perceive depth as well as an adult can. We have discovered that those of you who were breastfed as infants had better stereoacuity when you were 3½ years old than formula-fed babies. The same is true for those of you whose mums ate oily fish while they were pregnant, regardless of how you were fed when you were born. Now doctors have further evidence to advise expectant and new mothers on the benefits of a diet rich in fish oils and of breastfeeding.



In 2005 we revealed that your relationship with your dad in situations where your parents aren't together had a big effect on your behaviour. When assessed at eight years old, those of you who had little or no contact with your natural father as you were growing up seemed to find it difficult to adjust to new situations, tended to keep your feelings to yourself and became withdrawn. Those of you who had good contact with your dad, even if only on the phone, showed far fewer adjustment problems. As a result, we have been able to highlight the importance of good communication channels between parents, even when they're separated or divorced.



COELIAC REVELATIONS In 2004, 2,500 children in the UK were being treated for coeliac disease an intolerance to gluten, the 'sticky' substance in wheat and present in foods such as bread and pasta. However, analysis of your blood samples revealed that as many as one in 100 children may have the disease and that the majority remain undiagnosed until much later in life. The disease causes inflammation in the intestine and can make you lighter and shorter, but it's easily treated with a strict gluten-free diet. Thanks to you we've provided the medical profession with robust evidence, so that parents and doctors can look for coeliac signs and act upon

them sooner rather than later.



9 1 WORD RECOGNITION

In 2007 we revealed a connection between a child's word recognition and his or her hearing ability. We showed that those of you who'd had a condition called otitis media with effusion – which we commonly call 'glue ear', where the middle ear is filled with a sticky fluid – when young were slower to recognise spoken words. However, glue ear often clears up on its own, and we found that by the time those of you who had been affected were five years old, you'd caught up – that is, you were able to recognise as many words as children who'd never been affected by glue ear. As far as our researchers know, your data provided the largest study of its kind to assess the links between word recognition and different hearing abilities. Thanks to you the results offer doctors the appropriate knowledge to counsel families whose children are affected by

glue ear. We now know that, despite initial appearances, the long-term prognosis for speech and word recognition is very nearly always as good as for children who have never had issues with their middle ear.



# FIONA'S STORY BACK TO THE FUTURE

We keep all your data strictly confidential.

However, our Ethics and Law Committee believes we have an ethical obligation to share information with you if three key conditions are met. These are: 1. you have a treatable condition; 2. you've given us your consent that we should inform you if we make such a discovery; and 3. the data we have about you are of the same standard as that held by a medical doctor. Such a situation arises very rarely, but it did for Fiona.



'When I was about thirteen, Children of the 90s discovered I had scoliosis – a curvature of the spine. At that age, learning you have something wrong with your back is terrifying. At age sixteen I had spinal fusion surgery to straighten my spine. This has been perhaps the most significant thing to happen in my life to date – it was such a big operation. My memories of the experience are both good and bad – learning to walk again was slow and frustrating, but I grew closer to my wonderful friends and family - and I have a permanent memento in the X-rays showing my spine before and afterwards (see picture, right).

I was very lucky that
Children of the 90s spotted
the problem so that I could
do something about it. I now
know others with scoliosis
who are worried about surgery
and I would love to encourage
them. Although it's debilitating
at the time, the operation has
meant I can lead a completely
normal life. In the end it has
been a positive experience,
resulting in an immeasurable
improvement in my quality
of life for the future.'



Fiona's spine: before and after

# TWENTY ONE... DISCOVERIES ABOUT HOW WE'RE MADE

What is it that makes your bones strong or your circulation a biological super-highway? Why are some people prone to diseases such as asthma and eczema and others not? What links are there between our hormones and how clever we are? Does something within us give us our sense of identity? Children of the 90s has provided answers to all these questions, among others – here are 21 of them.

It is common knowledge that women have a biological clock that affects their fertility as they grow older. However, research into your dads, and analysis of information that both your parents have provided on how quickly they were able to conceive, has revealed that men have a biological clock too. We have shown that older men take longer to conceive a baby with their partner, regardless of the age of the mother. The odds of conceiving within six months reduce by two percent every year once the man reaches 24. Thanks to your dad, we have provided robust evidence for a male biological clock. From now on, when asked to investigate why a couple are finding it difficult to conceive, doctors will know to look at the man's age as well as the woman's.

**ECZEMA** One in five children suffers from eczema, a condition that causes dryness, itching and inflammation in the skin. Although we have known for some time that eczema runs in families, scientists have long believed that it is usually inherited from the mum. However, in 2004 your evidence proved that dads are equally involved. If only one parent has eczema there is a forty percent chance that their child will also have it; if both parents have eczema, it is 52 percent. In 2011 we combined your evidence with evidence from participants of 22 other studies to identify genes that can lead to eczema – to help doctors more readily identify those most susceptible.

FETAL BONES We have discovered that a pregnant woman's exposure to sunlight probably influences how strong a baby's bones will be. In 2009 we revealed that those of you born in the summer and autumn (so your mums were heavily pregnant during the sunniest times of the year) grew up to have longer, stronger bones than those born between November and May. As sunlight triggers the body to make vitamin D, we think it is this nutrient that helps the baby develop good bones, even before he or she is born.

### MIXED HANDEDNESS

In 2004 we published research that revealed that mums who experience high levels of anxiety during the middle of their pregnancies are more likely to have babies who use both their hands equally when performing tasks – called mixed handedness. Researchers asked more than 7,000 of your mums to tell us whether you used your right or left hand to perform six tasks (including throwing a ball, drawing, and holding a toothbrush). If you swapped hands for two or more of the tasks, we concluded that you were mixed handed. We compared our findings with the levels of stress your mums told us they felt at three stages during pregnancy. Those who reported high levels of anxiety at eighteen weeks of pregnancy were up to thirty percent more likely to have a baby who was mixed handed, or ambidextrous. So, although we know that handedness is a trait we inherit, we also now know that levels of stress hormones in the mother's blood during pregnancy can programme the baby's ability to use either hand for certain tasks.



STRESS RESPONSE We compared your mum's mood during the final three months of her pregnancy with your behaviour when you were almost four. We found that if your mum had been very stressed when she was pregnant, you were more likely to be hyperactive than the children of unstressed mums were. When you were ten we asked some of you for saliva samples taken at various times during the day, which we measured for cortisol, a stress hormone. We found that your cortisol patterns during the day were different if your mothers had been particularly anxious in pregnancy. This might help explain why hyperactivity was more prevalent in these children.

# GOBESITY GENE

There has been much speculation about whether or not obesity is a genetic disorder – and at Children of the 90s your data has helped clarify and highlight aspects of the debate. In 2007 researchers looked at information you'd given us to confirm that people with two copies of a particular gene variant (a gene known as FTO) were seventy percent more likely to become obese; a single copy increased the risks by thirty percent compared with people who had no copies of the gene variant at all. Then, in 2012 further research showed how 'epigenetic' codes might influence weight. Epigenetics studies how the environment switches our genes on and off, influencing when certain physical, psychological or emotional traits kick in. Epigenetic effects begin while we're still developing in the womb. We've learned that environmental factors that you were exposed to in the womb, such as whether or not your mum smoked, was anxious or ate unhealthily, influenced the likelihood of your becoming overweight by the time you were nine. So, while good nutrition and exercise are important to achieve a healthy weight, we now know that some of us are genetically more prone to obesity, and we think that events that occur

in the womb may also influence this.

**AUTISM SPECTRUM** Older mums (those over thirty when their babies are born) are more likely to have children with autism spectrum disorders, such as autism itself or Asperger syndrome. However, in 2010 we revealed a link between how old your grandparents are and your risks of developing a form of autism. We found that if your grandmother was over thirty when she gave birth to your mum, you were twice as likely to have an autism spectrum disorder. If she was older than 35, the risk increased to almost three times. So, perhaps a grandmother's age affects the development of the mum's eggs while the mum is still in the womb, in turn affecting the health of the grandchild.

HEART HEALTH According to a study published in 2010, pregnant women who put on excessive extra weight during pregnancy could have a baby who is more likely to develop a heart condition in later life. At the time when Children of the 90s mums were pregnant, it was typical practice for women to be weighed at every ante-natal visit – a system that had stopped by the middle of the 1990s. This makes data your mums gave us during pregnancy essential for looking at the links between your weight when you were in the womb and your future health. We compared how heavy your mums were when they were pregnant with you to the levels of cholesterol in your blood when you were nine years old. We found that if your mum had gained lots of weight, you had lower levels of 'good' cholesterol (which protects your heart) and that you were heavier, had more body fat and had higher blood pressure than those whose mums had stayed a healthy weight. From this we know that a healthy heart is in part a result of how much weight mums put on during pregnancy.





Among the things you've told us you remember most about your Focus visits as children are the toys and games we gave you to play with while you were with us, as well as the little rewards you got to take home with you. Here is a collection of some those bits of memorabilia - and some clues as to what we hoped they might tell us about you.



### **GOODY BAG GOODIES**

Bendy men, balloons and wristbands - do you have a favourite giveaway?



### **INSIDE THE DIORAMA BOX**

We asked you to peek inside so that we could see which of your eyes was dominant



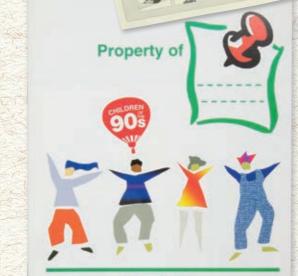
### **PEG TEST**

We used the peg test to take a look at your dexterity



### NUMBING CREAM

'Magic cream' helped ease the sting of injections



FOCUS @ 9





### **KEEPING IN TOUCH**

We've sent you food and activity diaries, birthday cards, newsletters, and more keeping in touch in every way we can



Vewsletter

**ASTHMA** Childhood asthma which can be life threatening - is on the rise. Why? In 2008 we revealed that if your mum had used a lot of chemical sprays and cleaning products shortly before and after you were born, you were between 33 percent and fifty percent more likely to have persistent wheezing problems up to the age of seven. We have also discovered that around 1.5 percent of you wheezed when you were between eighteen and thirty months if your mum smoked, and that asthma was more likely to develop if your mum frequently used paracetamol during the final stages of her pregnancy.

Several studies have suggested that what a mum eats during pregnancy affects whether or not a child develops higher blood pressure by age 7½. However, we questioned this theory because we didn't think these studies had enough participants or used the right methods to provide watertight results. There are so many willing families in Children of the 90s that we are able to draw more accurate conclusions. In this case we revealed that in fact what a mum eats during pregnancy seems to have no effect on a child's bloodpressure measurement at  $7\frac{1}{2}$  – and we believe that that would continue to be true throughout your life.

TOMBOY BEHAVIOUR We have discovered whether or not a girl grows up to be a tomboy is in part biological. In 2002 we considered whether levels of the male hormone testosterone in the mum's blood during pregnancy could lead to girls being born with a preference for boy-type games. Even accounting for whether or not you had older brothers at home, and whether or not your dad lived with you, it appears that at preschool age, at least, Children of the 90s girls preferred, for example, cars to dolls and rough games to gentle games if their mums had had high levels of testosterone during pregnancy.

At first glance at the results of our research, you might think the answer is yes. However, when we look closely the evidence isn't convincing. More than 6,500 of you had your height measured when you were 7½ years old. We compared your height with the information your mums had given us about their pregnancy diet. Although at first we thought that the better nourished your mums had been, the taller you were, in fact the links were very weak. In the end we decided there wasn't anywhere near enough proof to suggest that the two were in any way related. delibertellin

www.alspac.bris.ac.uk/discovery

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# OR DO YOUR GENES MAKE YOU TALL?

When we looked into our data on how your height changed over the course of your early infanthood, we saw that if you were at one time small for your age, you may very easily have been tall for your age the next time we measured you. This is called 'cross-centile' variation and it means that, over time, a measurement changes its position in relation to what we think of as average, rather than following a consistent pattern. We discovered, though, that as you reached three months of age, your genes kicked in. At three months you began to show signs of being tall or short for your age in line with whether or not members of your close family are tall or short.

In bygone times a pregnant woman would 'take to her chamber', taking full rest until she had the baby. Today we know that an active pregnancy is best. Eleven thousand of your mums filled in questionnaires about their daily activity levels - including how much they moved about while working, cleaning the house, walking or swimming. Once you were born we compared these levels to your birth weight. We found that busier mums had babies who were less likely to be small at birth. A significant number of you who were low birthweight had mums who had been fairly sedentary during pregnancy.

The first 'bionic eyes' are implanted to restore partial sight to two blind patients at London's Moorfield Eye Hospital

BOYS WILL BE BOYS In 2002 we asked 7,000 of our families how you liked to play. Of those families 300 of you had had no dad in the household since before you were one year old. We wondered whether boyish behaviour occurs even when a dad is mostly absent from a boy's life. We discovered that, yes, boys will always be boys. Ball games, war games, and rough and tumble were all still the preferred play for our boys, even when you lived with only your mums. We concluded that gender traits are part of the way we're made – and perhaps encouraged by influences outside our homes and that our parents have little effect on whether boys prefer 'girl stuff' or 'boy stuff'.

# TROUBLED DADS, TROUBLED BABIES

Although health visitors are trained to look for signs of post-natal depression in new mums, historically the emotional well-being of dads has been largely overlooked. However, we investigated the well-being of more than 8,000 Children of the 90s dads shortly after you were born, and compared the results with how you felt and behaved when you were  $3\frac{1}{2}$ . We found that eight weeks after you were born, more than 300 of your dads appeared to have some form of depression. At preschool

age we found that if your fathers had been depressed, you were twice as likely to have your own emotional or behavioural challenges than children whose fathers had not had issues with depression. The link was particularly marked for dads and their sons. Overall, we have shown that it's not only a mum's mood that influences their child's development, but also a dad's.





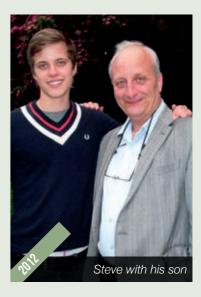
# STEVE'S STORY BEING A CHILDREN OF THE 90S DAD

Steve had no idea when he and his wife started to take part in Children of the 90s that they would still be involved 21 years later. Here he gives his view on being a dad in Children of the 90s.



'When my wife told me about a study that she had been asked to take part in, I was immediately intrigued. I'm an engineer (a scientist at heart) and, even though at those initial stages the work was to be about her and our baby, I was instantly interested in how the study would gather evidence and undertake its investigative work. I did everything I could to help by looking after our other children so that my wife and son could attend Focus visits.

The role of 'study dad' has evolved over the last 21 years. Dads provide fifty percent of the genetic material for the baby, but initially Children of the 90s focused mostly on the pregnancy, the mum, and the baby. It's fantastic that today fathers are asked to undergo



physical examinations as well as simply giving responses by questionnaire. I have had tests that have looked not only at my blood pressure, height and weight, but also at my bone density and how thick the walls of my arteries are. If we don't investigate the dad too, how can we get a true picture of "nature versus nurture"?

I am nothing but proud to be a study dad. I have been part of something that has helped scientists all over the world make discoveries that genuinely impact how we live today.'

**FAMILY PORTRAIT** In 2002 we published research that looked at pictures that 180 of you had drawn to represent your families when you were aged between five and seven. Some of you lived in 'traditional' two-parent families, some with one parent only, and others with a stepfamily. We wanted to see whether family bonds were biological or environmental - that is, whether you had a built-in sense of who your blood relatives are or whether vou accepted 'family' to mean the people living with you. Your portraits showed us that people have a well-defined sense of blood relationships, with step-relatives more likely to be left out of your drawings than your biological family.

In 2005 we revealed a link between low levels of the growth hormone known as IGF-1 and lower intelligence scores. At the age of eight, 547 of you completed an intelligence test and had your blood analysed for levels of IGF-1. The higher the levels of the growth hormone, the better you seemed to score in the verbal elements of the intelligence test. However, the discovery wasn't replicated in other elements of the test, which seemed largely unaffected by the levels of hormone in your blood.

In 2009 we looked at the weight records for almost 3,000 of the girls in our study and compared the statistics with body-composition X-rays (which show not only bones, but fat and muscle too) when they were between nine and ten years old. When you were twelve or thirteen, we also asked you to answer questions on your general health and well-being, including the date of your first period, if your periods had started We found that the more weight you had gained during the first nine months of your lives, the more likely you were to be overweight by the age of ten and to have had your first period early.

ALCOHOL TOLERANCE In 2005 we revealed how some of you reacted to your first alcoholic drink. We asked more than 1,000 of you, and eighty of you told us that you had had your first drink by the time you were twelve years old. We discovered that if you had a high tolerance to alcohol – that is, it took several drinks to make you feel giddy - you were more likely to grow up with alcohol problems. We think this is to do with your genetics and that those of you who drink to feel those effects will keep drinking until you feel them. As you get older, you'll need to drink more in order to feel intoxicated. This level of alcohol tolerance seems to be inherited and can result in alcoholism.

STRONGER BONES

Research teams have used our data to look at how we can make bones stronger, healthier and less prone to fracture. For example, when you were fifteen years old, almost 2,000 of you helped us to understand better how to improve the make-up of our bones. You wore an activity monitor for a week so that we could compare the amount of physical activity you did day to day with the thickness and size of your shinbone. We discovered that those of you who did lots of energetic

physical activity, such as jogging, dancing or playing sports, had increased bone density compared with those of you who did gentle exercise (such as walking) or no exercise at all. We now know that the strongest bones develop in those who lead more active lifestyles.



# PART THREE: JOURNEYS INTO THE FUTURE

# LOOKING FORWARD TO THE NEXT 21 YEARS

When Jean Golding founded Children of the 90s, she knew that for the study to prove truly valuable it must continue to thrive for at least 21 years and more. There is still much to learn – so many links and patterns we have yet to discover. In this chapter we look at some of the research that is currently underway thanks to your ongoing commitment. We celebrate the generations of participants who continue to make the study possible, and finally we look forward to welcoming the Children of the Children of the 90s – the next generation, whose lives make the prospect of continuing for another 21 years more possible.

80 JOURNEYS INTO THE FUTURE 81

# TWENTY ONE...

# WAYS YOU'RE SHAPING THE FUTURE

**Albert Einstein once said**, 'I never think of the future, it comes soon enough.' He was right, of course, but there are so many exciting developments happening, every week, even every day, thanks to your data, that we asked our researchers to give us a sneak peek at some of the projects they're working on now. Here are just 21 examples of research that is underway.

HORMONES AND THE HEART Did you know that girls have higher levels of male hormone (testosterone) than female (oestrogen) in most parts of their menstrual cycle? Particularly high levels may lead to irregular periods or excessive body hair. We measured your testosterone levels when you were fifteen and asked you about your periods. In the future we'll use these data to see if there's a link between female testosterone levels and an increased risk of heart disease.

UK 10K — LOOKING AT GENES We're part of a project called UK10K, which aims to collect detailed genetic information from 10,000 people in the UK, some of whom have a disease, and some of whom are healthy. Through studying the whole genome (the 'instruction manual' present in every cell in our bodies, making us who we are) using great advances in technology, we will further understand the role of genetics in the complicated web of factors that lead to disease.



# 3 IDENTIFYING ASPERGER SYNDROME

At age six you drew six facial expressions (a happy face, a face yelling and so on). One characteristic of Asperger syndrome is difficulty in reading emotions, ALSPAC data have already shown that the average age at which Asperger syndrome is diagnosed is significantly older than for other autistic spectrum disorders. In the future we hope to see whether or not your sixyear-old drawings provided early signs of which of you would go on to develop the condition, so that doctors can use the test to diagnose Asperger syndrome earlier.

### FOCUS ON MUMS

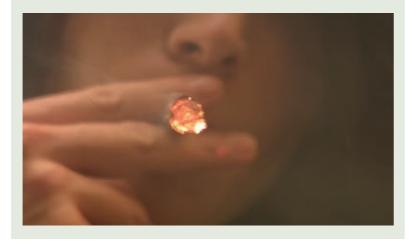
Over the next six to seven years we'll be examining the information your mums have given us in much more detail. We'll be looking at when their periods started, how many times they've been pregnant, how their bodies changed during pregnancy – and how that might affect other aspects of their health, and yours. We're particularly interested in your mums now because most are in their mid- to late forties or early fifties, which is a time of change in a woman's life. Some are going back to work after being a full-time mum, others may be considering retirement. Some may be coping with an 'empty nest' as you leave home, others are busy caring for elderly parents. It's also the time when a lot of women start to go through the menopause. What this means for women varies a lot depending upon the society they live in, how they see themselves, their health and their emotional attitude towards the menopause. We'll be conducting in-depth interviews because, aside from what is happening to women's bodies biologically or medically, we also want to know how your mums feel and think about themselves. Our research will show us how women's health and well-being changes over time, what causes these changes and how the changes affect all aspects of a woman's life. We then want to give doctors the information they need to work out how to ensure women stay healthy and feel good into older age.

BOY POWER We're investigating whether rising levels of the male hormone testosterone during a young man's adolescence affects nerve fibres – or axons – in his brain, which might affect his mental health. Axons help cells 'talk' to one another and if the communication breaks down, a young man may develop conditions such as depression or schizophrenia. Using non-invasive brain scans, we want to look at your brains to explore whether there's a link between unusually high or low rises in your testosterone and your risk of having mental health conditions.



### LOOKING AT THE WAY YOU SMOKE

Smoking accounts for approximately six million deaths per year. In order to develop new, effective treatments to help people stop smoking, it's very important that we understand the biological causes of tobacco addiction and dependence. Research into data you've given us at special smoking clinics looks at the biology behind smoking behaviour, such as the way in which you smoke a cigarette – including the number of puffs you take and how much smoke (and toxin) you inhale. Better understanding may help doctors and other researchers to develop new strategies and treatments to help people quit.



BROTHERS AND SISTERS In the future we'll be asking all your brothers and sisters to join the study. We know that over half of you have one sibling (brother or sister), almost a third have two siblings and more than ten percent of you have three or more. Over the last 21 years, we have gathered a lot of information about you and one or both of your parents. If we can include your siblings in the study too, we can compare what we know about the rest of your family and your brothers or sisters and use the information to improve our understanding of how and why health and well-being cluster within families.

UNDERSTANDING AND PREVENTING DEPRESSION

We know that between eighteen and 24 years old you are particularly likely to suffer from depression and anxiety – the incidence of disorders such as these increases rapidly at this age and it peaks between the ages of twenty and thirty. The information you give us at this crucial time in your lives will help us to understand the origins of depression and other mentalhealth issues. We'll be able to establish the extent to which an episode of depression affects how well you do at college, the kinds of jobs you get and how easy you find it to form successful relationships. We'll compare your feelings now to whether or not you 'self-harmed' when you were a teenager. In the future we hope the information you've given us will help doctors to find ways to prevent a young person's first episode of depression, and as a result help treat depression throughout his or her life.



84 JOURNEYS INTO THE FUTURE FROM THE ALBUM: GENERATIONS 85

FROM THE ALBUM

# **GENERATIONS**

It all began with a conversation with your mum and before long we were talking to your dad too. Through them we got to know you, and now we are lucky enough to be welcoming some of your own children into the study. Here are just some the people who are part of Children of the 90s.



### THEN AND NOW

Hannah with her stepdad Martin and her mum Hilary (left) and smiling for the camera, aged one (above)





Mum Kate holds Sophie (left)
in her bridesmaid's dress, and
(above) Sophie is off to the prom





#### KATE AND TOM

On the left, two-year-old Tom sits on his mum Kate's knee, and (above) Tom and Kate now, with Tom's sister Abi (not in the study yet)





#### THE NEXT GENERATION...

A study family awaits the next generation, with mum and dad sitting either side of their daughter Lizzie during pregnancy. Lizzie's brother stands on the right next to her baby's dad. Above, baby Eliza is now part of the family

SUPPORTING PREGNANCY Data we've collected from you and your mums suggest that your mum's emotional state during pregnancy can have longlasting effects on you: deep anxiety or depression during pregnancy doubled the risk of emotional and behavioural problems at least until you reached thirteen years old. These findings are starting to influence Government policy to focus attention on providing lots of emotional and practical support to women during pregnancy, such as through the Family Nurse Partnership.

Different people have different versions of the same genes. This is what makes us all different and why every one of you is so important. Variations in a version of a gene called APOE have been linked to differences in how people aged over sixty think and remember things. Using DNA from your blood samples, we can find examples of all the different variations of the APOE gene to understand how each version affects our ability to think. We hope the information you give us might lead to better prevention of dementia and associated conditions later in life.



You have helped us to understand why some people develop mental disorders and others don't. We now know that some symptoms, such as hallucinations, which we used to think of as characterising major mental disorders, are in fact quite common among young people. We have come to understand that only very occasionally do such symptoms indicate a problem. Magnetic Resonance Imaging (MRI) scans of your brain give us insight into how the brain develops and what changes take place to mean that hallucinations are a warning sign in some people and not in others. In the future our findings may help doctors identify and treat those at risk.

In April 2012 we published research that indicated that the way in which a pregnant mother's blood pressure changes over the course of her pregnancy could be a sign of how likely she is to develop pre-eclampsia – a dangerous condition in which the mother's blood pressure increases, putting the health of the mum and the unborn baby at risk. Researchers used data from 13,000 of your mums to suggest that by monitoring the rate of change in blood pressure from early in pregnancy, doctors may be able to identify those women at potential risk of developing pre-eclampsia - meaning they can take steps to treat it before it becomes a problem.

In the largest study of its kind ever undertaken, we have been looking at your arteries since some of you were only nine years old. We now know that between the ages of nine and eleven, some of the risk factors associated with heart disease were already there. In the future this research, as well our continuing investigations into your heart and arteries using scans and looking at how fast your blood flows, will help us learn more about when and how heart disease starts. We hope this will help other scientists keep us all informed about how best to keep our hearts healthy.



We know that stress incontinence (leaking urine when you sneeze, cough or exercise) and urge incontinence (leaking before you get to the loo) tend to be inherited and that they might also be caused by other factors such as pregnancy and childbirth. However, we haven't vet identified variations in your genes that underpin the family link. Your mums' participation in Children of the 90s allows us to test the effects of genetics (nature) and the environment (nurture) on the development of bladder problems so that in the future doctors can predict who is at risk of developing incontinence and go on to treat those people more effectively.

# TIME FOR DADS

Other studies of men tend to recruit in middle age and generally concentrate on heart disease, cancer and other chronic diseases. At Children of the 90s, we want to look at the bigger picture. We've been gathering information about your mum's male partner's physical, psychological and emotional health since the start of the study, when he was aged between fifteen and 65. Unlike other studies, we also look at social, economic and psychological factors, such as family income, the make-up of families and households, and issues relating to fatherhood. In fact, we were the first study to show that men suffer from postnatal depression. In the future we plan to explore issues previously untapped in the field of men's health. For example, we'll look at whether the age at which a man becomes a father affects his health. We'll examine the relative influences of mums and dads on their children, in terms of both genetics and the family environment. Even further in the future, as your dads start to age, we'll look at a variety of ageing traits, such as cognitive function and physical performance, as well as conditions such as depression, heart disease and diabetes.



# ROO'S STORY

### **CHANGING MY LIFE**

One of the youngest participants, Roo's\* childhood was far from storybook. Being part of Children of the 90s has not only been invaluable to the study, it has inspired her to change her life.



'I'm twenty years old and married with two gorgeous stepchildren. I work with 300 under-five-year-olds in three different work placements, where I can teach the children to flourish. I want to help them to feel secure and loved so they don't have to grow up the way I had to. If it weren't for Children of the 90s, I may never have taken an interest in childhood development in the way I have now. When I was young Children of the 90s gave me the power to notice that things were different for me.

My childhood was marred by abuse – by my parents and others – and as I grew up I became resentful of anyone in authority, and also of other children, who appeared to have a loving, caring family. At Children of the 90s, though, I felt safe – the staff were kind, and they made me feel valued and part of something really important.

Learning to overcome such a difficult start has been far from straightforward, but I was determined that my adulthood would be a happy one. A large part in my development has been finding my faith in God. I'm able to match the religious aspects of my work with my understanding of science, gained as a result of being part of the study. Through both, I have been inspired to change the course of my life, and to help the next generation.'

\*Not her real name

THE CAUSES OF BREAST CANCER Breast cancer affects about 48,000 women in the UK each year. By using non-invasive Magnetic Resonance Imaging (MRI) to study the water content in women's breasts, as well as measurements in the blood and urine, we hope to learn more about the hormones and genes that affect the structure of breast tissue. We'll compare our results with data we hold about growth in childhood and also (with their permission) with the results of your mums' breast screening mammograms. We hope the study will improve our understanding of what causes breast cancer much later in life to help us prevent the disease in the future.

Obesity affects nearly a quarter of people over the age of sixteen and, at current rates, by 2025 nearly half of all men and more than a third of women will be obese. We want to use new technology in the form of a 'Mandometer' to record the speed and pattern with which you remove food from your plate, so that we can understand why you might put on weight. A portable weighing scale connects to a small computer and will monitor the speed at which you eat. We want to use the information to help nutritionists develop ways to encourage



DATA LINKAGE Now that you're adults we have asked you to contribute to yet more groundbreaking research into the causes of the world's most important health and social problems. We have asked you to allow us to collect information from other sources, such as your NHS records, your school and even your criminal record if you have one. This form of 'data linkage' enables us to fill the gaps in information we've gleaned at Focus visits so that in a few years' time our research can become fully inclusive, excluding no one and leaving no stone unturned.

SAFEGUARDING THE FUTURE With the successful recruitment and increasing involvement of the Children of the Children of the 90s, in the future ours will be the only study in the world currently able to understand the impact down through the generations of risk factors in pregnancy. It will be unique in its ability to measure the repercussions of major changes in society, such as shifting trends in diet and lifestyle, and the advances in technology and social media, on the different generations within families. Our data-bank will be a unique resource that draws upon information from your parents, you and your children too - and available to bona fide researchers all over the world. Children of the 90s will be seen as a landmark study in the way that medical researchers view Framingham (a US investigation into heart health that began in 1948) or Whitehall (a UK-based, 1960s study that looked at how social status affects health). It will be one that all scientists and doctors interested in understanding the nature of illness, disease and genetic inheritance will know about and use. And that's thanks to all of you.



**Affectionately known as 'COCO90s'**, the Children of the Children of the 90s are the newest participants in our study, helping us all to look to the future.

The birth of a new generation is always full of wonder. For ALSPAC it has the potential to become groundbreaking. We hold a wealth of biological and social information about not only you, but your parents too and this puts us in a unique position. If, with your permission, we can welcome your children into our study, we can begin to

collect information about three generations of families. We can look at how the lifestyle, health and well-being of your mum and your dad might have affected not only your own health and well-being, but how it might affect that of your babies too. We'll also examine factors that influence how genes are expressed – this is known as epigenetics.

COCO90s is already underway, collecting data from some of you in your new role as parents, via questionnaires, samples and special Focus visits. Thank you to you and your beautiful babies for letting us remain part of your lives.



# SARAH'S STORY WE'VE BEEN TO EVERY FOCUS VISIT



Sarah and her family left Bristol when her study child was one year old, but she and her family were all determined they would honour their commitment and keep coming to Focus visits. Here she describes how attending appointments became a meticulously planned family adventure, involving long train journeys and cosy overnight stays.

'Initially the children my "study" daughter and her brothers – all loved attending sessions, delighted to be rewarded with bouncy balls and coloured pens. As my daughter approached her teens, rewards came instead in the form of high-street vouchers and her brothers began to lose interest. Instead, the trips became mother-anddaughter-only events. My daughter and I would check into our hotel and spend the evenings snuggled under our duvets, watching movies and eating pizza. After our Focus visits my daughter would march me from the study centre to Broadmead, where she'd try on every outfit in Top Shop that caught her eye. It was the best of times – and the most expensive.



Coming to every Focus visit has made being a study family a hugely bonding experience for us. Now just turned twenty, my daughter has been away at university for two years, but we still reminisce fondly about our trips. And now it's my turn, and I am invited to attend a 'Focus on Mothers' session without my daughter. I'm still undecided whether to make the journey alone – after all I don't think I could manage a whole pizza on my own.'

**Children of the 90s** doesn't stop here. There is still so much to learn from the information you've given us and we want to go on gathering data for as long as you want to help us. Here some of our scientists look forward to what might happen in the next 21 years.

#### **SMARTPHONE DATA**

In five years' time we predict that if you prefer we could collect your data in innovative ways that don't inconvenience you. Rather than coming to Focus visits, you may be able to feed us information from smartphones, which could also feed us information about such things as your exercise regime and your food intake. With your consent, we might even assess your travel habits via your phone's in-built GPS.

#### DEFINING THE EPIGENOME

There's an international initiative underway to describe the 'human epigenome' – how environmental influences affect how our genes work. Our epigenetic analysis of 1,000 of you and your mums is making a major contribution to this initiative. Within the next five to ten years, we hope scientists may begin to use epigenomic information to more accurately predict disease and target treatment, as well as to develop new medicines.

#### STEM-CELL UNDERSTANDING

A stem cell can renew itself and can generate different cell and tissue types, such as heart, nerves, kidney and liver. A stem-cell resource based on Children of the 90s will provide researchers with state-of-the-art tools to study and understand development, ageing and answer many questions about disease. We hope to establish the stem-cell aspect of the study over the next five years and within ten years your stem cells could be used for research into many health issues.

### **CLEAN LIVING**

Within the next fifteen to twenty years, we hope that researchers working on our data will be able to develop a series of Internet-based videos that can help teach teenagers how to control impulsive behaviour. For example, someone who is more prone to alcohol or drug problems could use these videos to learn ways of coping that might in turn help reduce the levels of alcohol and drug abuse in the next generation.

#### BETTER HEALTH FOR HEARTS

In fewer than 21 years' time, doctors may be able to use genetic information to help predict those at risk of heart disease and consider when to begin treatment. There may even be the chance for us to manipulate expression of the relevant genes in order to prevent disease, long before it becomes a problem. The opportunity to practise preventative medicine could improve the quality and length of life of those affected, and also reduce the economic burden of disease.

#### GENERATIONS OF INHERITANCE

In 21 years' time generations of your families could have shown us that our biological make-up is far more than just the genes and other DNA patterns you inherited from your parents. By 2033 it may be common knowledge that a baby's early development also reflects what his or her parents and grandparents experienced in their early life. Much of this ancestral memory could be understood in terms of chemistry – a molecular imprint that is passed through the generations.

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For more information about Children of the 90s and all the research referred to in the book, or to download a free pdf of the book, visit www.childrenofthe90s.ac.uk/go/21st-book



Twenty one years ago we asked thousands of parents-to-be to allow us to follow the lives of their newborn babies in order to shed light on some of the most important health and social issues facing the world. This book is our way to thank all those parents and their children - now young adults - who have given their time and dedication over the last 21 years so that scientific discoveries fundamental to our understanding of how to improve the way we live today could be made.

From all of us to all of you, thank you.



Avon Longitudinal Study of Parents and Children

