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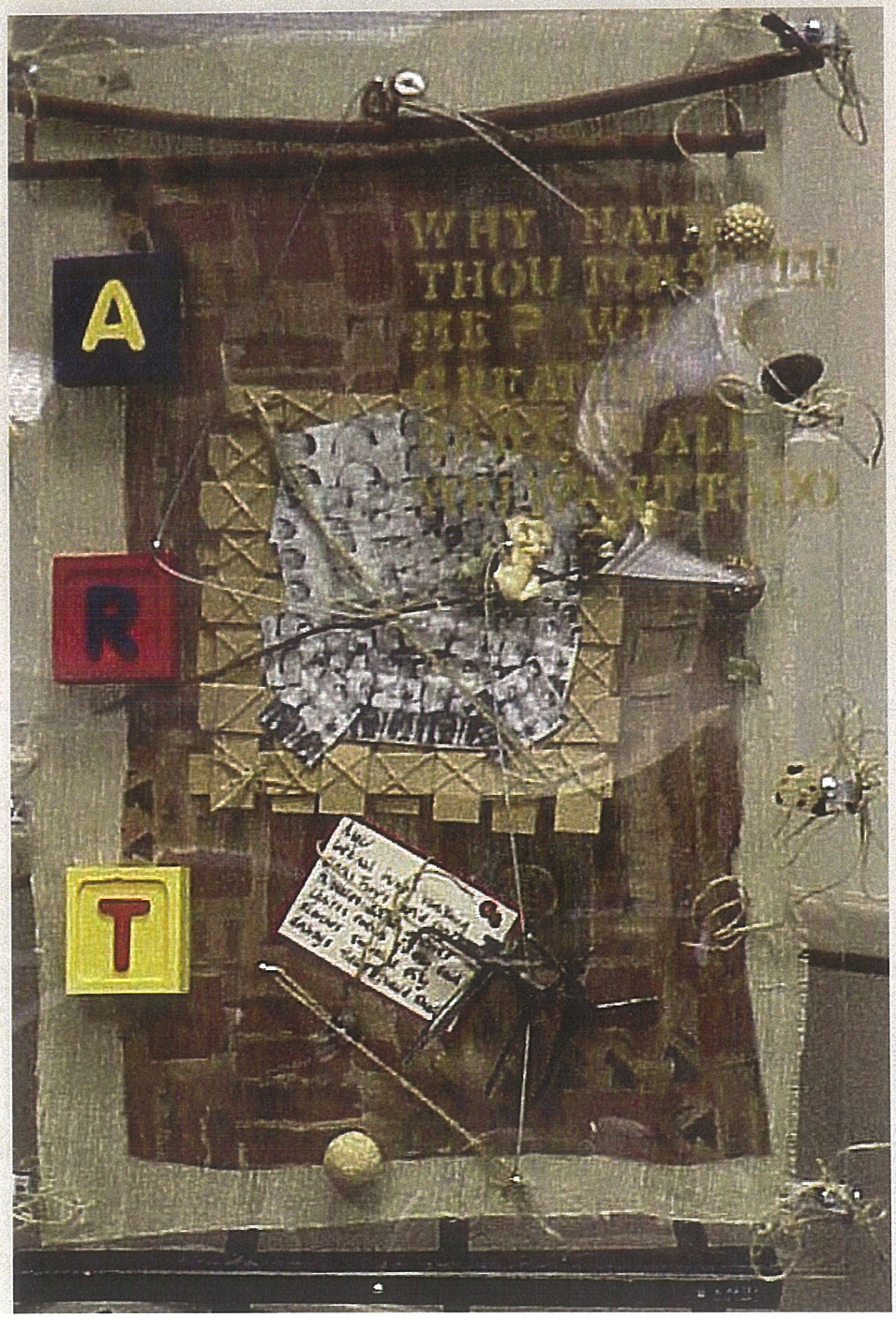

NEWS VIEWS REVIEWS AND MORE

inform the readership of your views and concerns.

Lastly, I would like to congratulate Paul Crowther for his sterling work as editor of the journal – he has made it a vibrant and interesting read which I (for one) looked forward to reading when it arrived through the post. Also a big thank you to Dani Singer for her hard work as book reviews editor – I know from writing reviews that she worked hard to encourage you and was unfailingly pleasant in her feedback. We are very lucky to have Tricia Thompson-Newby as our new book reviews editor. I have published the book reviews guidelines to encourage more members to come forward and contact Tricia saying that they would like to review a book. You keep the book and it is a good way to start (academic) writing.

Front cover

ART, Why Hath Thou Forsaken Me? When Creating a Baby is all You Want to Do

What is art? Through the ages it appears to have represented many things from the exalted to the functional; an object of beauty and as likely, despair. Art in this century has also emerged as the acronym for ***assisted reproductive technology***; an ironic restatement of the quest for fertility. Art implies creativity, facility, brilliance, flair, a wonderful antagonist to the forlorn condition of the *infecund*, where even this word sounds desolate. This poster unites some of the elements of technology that have brought us to the present in reproductive medicine; compressed between plastic, the symbolic petri dish, against a backdrop of fabric that speaks to the thread so fundamental to an individual's story. The reduction of the human being to a failure of seed or egg begets grave questions of faith, not simply of those powers we believe to exist outside of our selves, but that examine the very center of who we seem to be. Once non-procreative, it appears many people struggle with the idea that they can continue to be creative at all; still capable of visionary themes.

Technology has allowed us to fashion instruments that might get to the heart of a mechanical dilemma, even sort out a system error or two. However, it can also keep us tethered to a diminished view of our own potential, spike anger, doubt, and a bereft lament of loss unopposed by an inspired conviction that we are still larger than whatever ails us. We can be reduced by science and its essential request that we are only what can be measured and seen, or we can unbutton the tie that insists we are defined by the those things we do not seem to be.

Front cover designed by Liz O'Donnell with this explanatory text.

Point of intersect

(Liz O'Donnell and Robert Edwards, ASRM Washington , DC 2007)

Point of Intersect: Where Hope Meets Science

A Conversation with Robert Edwards

In the summer of 1984 I took Robert Edwards and Patrick Steptoe's book *A Matter of Life* from the library and read it six times.[1] Both men were familiar to me as 'the fathers' of in-vitro-fertilization' (IVF) and I had watched the 1978 coverage of the birth of Louise Brown with the kind of shrouded prescience that leaves one knowing something without knowing what. My current memory of Robert Edwards holding the world's first test-tube baby in his arms sits somewhere between the day I received my immigration papers for Canada and the death of my sister, which simply put, means it is right up there. When the label infertility was used to describe my own discordant search for family in 1984 I had already moved through teenage cynicism, beyond young-adult idealism, into mid-twenty something, apologetic conformism. I certainly was not prepared to hear or live the invisible stigma of involuntary childlessness. Infertility for me was not only a word that defined a painfully unjust outcome, it was a soul- destroying acronym for nihilism. I could not quite explain, back then, why not being able to have a baby felt like an invitation to my own untimely death; but for years after being told I was infertile, my lungs seemed constantly short of breath.

Following my sixth reading of the book I had acquired some mastery of the science of assisted reproductive technology (ART) and was also captured by the men whose deeper lives were pressed between the words on the page. Robert Edwards wrote several more chapters of the book than Patrick Steptoe and I projected that it was likely Edwards' compulsion to discover how human eggs could be penetrated by sperm and develop in-vitro that drove the success of their work together. Neither man could have reached the pinnacle without the commitment and passion of the other, but Robert Edwards' obsession seemed demonic. Demonic in the sense that it was relentless, intense, and unwavering; infertility is like that. It sucks the blood from your heart in drops of sadness that plunge without forgiveness into an infinite black space. *A Matter of Life* was my search for a bottom to my infinite black space; it was hope and commitment rolled into one glorious offering. Hope is not a scientific word. Hope can be gentle in the hands of poets and a gasping emptiness in the mouths of men and women who cannot bear to speak or hear an unconfirmed truth. But when hope and commitment merge, they create beautiful points of intersect that

have the potential to flourish. Robert Edwards and Patrick Steptoe are one of the twentieth century's beautiful points of intersection.

By 1986 I had undergone at least 8 intrauterine inseminations and two cancelled and one complete IVF cycle without a pregnancy. As well as being bereft, I felt isolated and hostile and viewed the minutes of my life in hormonal shifts that threatened to break what spirit I had left. To put my emotions in perspective, infertility did not descend upon me in a vacuum; infertility invaded every cell, but cells that had been in existence for twenty eight years and carried the memory of each loss and triumph along the way. The memories and what they measure were not the cause of my infertility but they were the narrative through which I constructed new meaning. When I read Patrick Steptoe and Robert Edwards book I did not just discover two scientists whose work might one day help me to grow a child inside, I observed the mirror-image of my own grief in their quest for discovery. I also understood that the relationship between John and Leslie Brown, (Louise Brown's parents), and the fathers' of IVF was embedded in the marrow of their experience together and I wanted to be part of that experience.

In 1987 I travelled to Bourn Hall Clinic from my home in Toronto and underwent another IVF cycle. I was one of Patrick Steptoe's last patients. He was still making bedside rounds albeit leaning heavily on his walking stick, and when I met him I was mesmerized as though in the presence of God because to me he was the messenger of something greater than I had managed to find alone. This confession is not intended to elevate the man to deity but reflects the resurrection of my faith in something I felt short on during medical treatment; simple kindness. I had no need for anyone else to tell me my odds of getting pregnant, it did not change the side of the equation I wanted to be on. What I longed for was divinity and humanity dressed in science.

I did not become pregnant in September 1987 and when Patrick Steptoe died in March, 1988 I mourned his death like one does a father because I believed that he had paved the way for my future and I had not said thank you. Robert Edwards eluded me during my trips to Bourn Hall although I knew it was the work of his hands that had given us our frozen embryos. I returned to England to have those embryos transferred in May 1988 and finally became pregnant. Our son was born the following February and his birth is the demarcation point in my life between self-absorption and selfless devotion; (it is true what they say about stereotypes and clichés).

Life moved on over the years and I had another child, also through IVF. The accounts of our family's conceptions were shared as miracles at the dinner table, as bedtime stories, and on the night before Christmas. Our boys knew the names of Patrick Steptoe and Robert Edwards like other children know grandma and adolescents are introduced to Einstein. In our house Steptoe and Edwards are not remote potential Nobel Laureates, they are the men who personally brought over a thousand lives into being and have been indirectly responsible for the creation of a million or so more; they gave us our sons.

Despite becoming a mother I have not put down infertility. Infertility is emblematic of what I have learned and am still learning: humility, patience, resilience, compassion, deference, gratitude, forgiveness, and love. Infertility helped me to understand the nature of connection, the myth of motherhood, and the unyielding desperation that pervades a broken heart. It also taught me something about science and ethics. Since 1990 I have dedicated my life to working with individuals and couples who struggle to have and keep their children, and have simultaneously maintained my parallel quest to one-day thank Robert Edwards personally. That day came in October, 2007 when Robert Edwards agreed to meet with me in Washington D.C. while we were both

attending the American Society of Reproductive Medicine's Annual Conference. Ironically I bumped into him the afternoon before our scheduled appointment and flustered and in awe, like a giddy teenager in the presence of her idol, I placed my long letter of thanks into his hands. He was gracious, brusque, and funny in the way that only a Yorkshireman can be and his tactile conversation helped me to shake off my idolatrous nerves before our formal meeting the following day. I wish I could share here what he said to me during our impromptu encounter but it was off the record. His language was peppered with idiosyncratic jargon that displayed his ongoing passion for scientific research and his commitment to academic transparency, juxtaposed against the frailty of age (his and mine), and immersed in the profound respect that I am still consumed by today.

Infertility treatment is a daring challenge to intimacy. It forces relationships between people who under different circumstances might not even choose to sit next to each other on a bus and strips away, without apology, any veneer of privacy. Every question is fair game, from the style of one's underwear to the regularity of cycles and sex. I have heard myself describe Robert Edwards as "the father of my child" as though my partner has been justly relegated to that pitiful space off the infertility clinic waiting room littered with outdated porn. For me child-ache was a private yearning that trampled every conviction I had and upended what I thought it meant to have purpose. I could not reconcile the emotional turbulence of infertility with my intellectual assertion that I could survive without giving birth, which meant that I was forced to explore how I believed I was connected to the value of my own life. Maybe this is the charge all human beings must consider at some stage between their birth and their death?

Patrick Steptoe and Robert Edwards have assumed their place in science and history and perhaps more importantly, beyond the pure brilliance of their discovery, they have invaded countless hearts. I wanted to ask Robert Edwards about his experience at the point where hope and science intersects. I have fantasized that his life might somehow reflect my own prophetic journey through IVF; as if by cosmic prediction. I am intrigued by the ill-defined yet nevertheless magnetic attraction that exists in the space between him and me and I can't decide whether it belongs to my imagination, or whether some greater undetermined mechanism is at play? Synchronicity has the ring of poetry but even scientific discoveries can be revealed through perfectly timed ineptitude, coincidence, and mistakes. It took me almost two years to capture forty five minutes of Robert Edwards' time and involved creative subterfuge, persistent correspondence, enduring pleas thinly disguised as nonchalance, and the reluctance to give up, not unlike the demands of infertility. Our conversation represents a reunion between two people who have never met and is a form of unilateral wish fulfillment that has empirical merit because it is no longer needs to be created in my mind's eye.

I began by asking Professor Edwards what his work has meant to him personally and he told me "...it has meant a lifetime" as though *A Matter of Life* is the endless refrain that defines his own purpose. He grew up in a working-class family in England, the middle child between two brothers, Sam and Harry, and describes his childhood as happy although, "...we had to get out and earn the money and then join up together and enjoy it together." He also had "...very much a working-class type of education but the best type of working class..." Robert Edwards was not born into monetary or academic wealth and came of age at a time in England's history when excelling beyond one's social station required the gift of chance as much as true grit. Between military service and bucking determinism Robert Edwards could have slunk beneath his talent but he also had a mother whom he credits for "changing the course of his life" [1]

He grew up with his own idols, Ernest Rutherford, (who won the 1908 Nobel Prize for Chemistry), being one of them. Is it no small coincidence that Edwards ended up marrying Rutherford's granddaughter Ruth? Perhaps this is another glorious point of scientific and poetic intersect or maybe perhaps love is, after all, not so blind?

Robert Edwards is unapologetically confident about the work he has achieved and is equally deferential toward the collaborative efforts of his colleagues and his peers. He has made a huge space in his heart for the scientists who came before him and seems uncomfortable with anything that smells remotely of adulation. Above all he believes that he has learned from, and been motivated by, the men and women who were his gurus on his search for discovery. People like:

"Professor Waddington who was a brilliant microbiologist and wonderful colleagues, like Bunny Austin in Cambridge, Patrick Steptoe, Jean Purdy who was fabulous, and another person who stimulated me was Jean Cohen...I'm inspired, and continue to be inspired by my colleagues and I think they're inspired by me. It would be a fool who didn't realize that his teacher is probably the most important person in his life. I look back at my teachers with immense pleasure. I wish they were all alive today, I really do, but life isn't like... I could list, even from my school days. I could tell you the names of my teachers..."

Robert Edwards slips easily between hope and science. His words are a surprising mix of sanguinity and nostalgia periodically reigned in by a methodical urge to keep things in the right perspective. He was not comfortable with my question, *what is your experience of having impacted the lives of so many people?* "Modest" he said, as though I too needed to remember that his work represents the sum of many parts; points along the way that whether through wisdom or fate had to find their own place of intersect. Edwards brought the word 'luck' into our conversation. Not the sort of luck that makes people purchase lottery tickets after seeing a black cat, more a respectful appreciation for the contrivance of circumstance:

"I think I've been ***damn lucky*** *to be candid...just when things have been needed, a change has been needed there has been somebody there to help me over the next step and that's how I have developed."*

His words have a resonance that shadows my own experience and I still do not know whether this means that we make things happen or that we construct importance from their happening. During my research for my doctoral dissertation I came across several interviews with Robert Edwards, and his teachers feature prominently in his words of gratitude, in particular the developmental biologist and geneticist Conrad Waddington, whom he mentions above. Waddington was of special interest to me because he was a researcher who valued poetry, philosophy and the nature of the relationship between science and art; a relationship impacted as much by creativity as it is dictated by chance[2] Waddington was not interested in the ART that we now know of as assisted reproductive technology but the artistry of a beautiful mind, the kind of mind that considers uncommon points of connection between equally important things. Waddington was Edwards' mentor and Waddington's 1969 book *Behind Appearance: A Study of the Relations Between Painting and the Natural Sciences in this Century*, is an astounding original analysis of how great discoveries get made and "...emphasizes the 'leap into the dark' by which a creative scientist arrives at a new concept"[2] (p.101). Edwards is a man who has taken many leaps in the dark:

"I've got so much to tell. I was just thinking today even about tiny little things, tiny little things... I've had wonderful endings...the big things, you know, the day when we saw the first egg mature in vitro, the human egg...we didn't know how to fertilize the

egg and Bobby Bannister and I did it together and we'd got to climb into the damn building at midnight to do it because after the eggs matured then we had to fertilize them and that would take another 6 hours...and the next day the press said there had been a very suspicious story about you creeping about at the lab at night...it's true... then to find out one of us forgot to take the key to the gates so we climbed over the railings and then the press said "you've been climbing over the railings what is secret about it?"

Robert Edwards is not a man of mystery; he is interested in the mystery of the natural world. He is a man with a mission and boundless opinion who grew to become who he is because he doesn't rest. He gets up at 4 o'clock in the morning to review scientific papers for his on-line journal, he travels around the world to give lectures and presentations, he challenges young minds to think beyond the confines of what is under their current slide, and once in a while he makes time to contemplate with ex-patients' the magic and disappointment that stain the meaning of peoples lives:

"...I'm very touched by the patients and my deepest sympathy goes to those who failed because I know exactly what it means to them."

As much as his quest for new science has brought the name of Robert Edwards to the forefront of reproductive research it his connection to humanity that drives my urge to know him.

Like Edwards I too began life in relatively austere circumstances, the middle child of triplets, (achieved *without* assistance of ART), as well as one of seven children brought up in a single-parent home. I was not a friend of science it seemed too verifiable to me and I lived in fear that someday *I* might be found out. Art and beauty had no solid reference point either; merely abstract forms that occupied a space beyond the squalor of a low-end council estate, although sometimes beauty had long blonde hair. I viewed art as if it was somebody else's disagreeable idea and my notion of parenting and heritage was disagreeable too. As a teenager I insisted I did not want children because I hadn't felt much like anyone's child, only to find out when there was a possibility I couldn't have them that I had no desire to be on the negative side of an unbalanced equation. Now it seems to me that children are the spiritual realization of the natural order of things as well as the physical manifestation of our human body; maybe wanting children is never really about the children, is it? I mean after all they aren't here yet. Maybe wanting children is perhaps in part about finding the point in our own existence that can be pacified by regeneration, if the decision to procreate is ever that thoughtful.

Robert Edwards has five children, all of them girls, some of whom have even struggled with infertility, which for some poorly-considered reason really surprised me. How could it be that one of the fathers of IVF has any daughter who cannot get pregnant? *"...there's nothing special about us"* he said, *"...they weren't immune from the rules of evolution."* This was one of several points in our conversation where I took him off his pedestal only to place him back again when he was not looking.

Robert Edwards is an ethical man. He stands on his opinions and for his opinions. He has been alternately vilified and praised throughout his career, and although he respects legitimate challenge he strikes me as someone who will not acquiesce for the sake of keeping a dishonest peace. Robert and Ruth Edwards had their children the 'old-fashioned way', as did Patrick Steptoe and his wife Sheena, and yet each of them connect with the grief of involuntary childlessness as though their offspring's existence depends on giving infertility legitimacy:

"Well, I needed a lot of people to get through, number one. I had to convince a lot of people and there were people who wouldn't be convinced so it was a damn big fight and when I was fighting I

wasn't fighting for myself, I was fighting for my patients' and for my children by the way as well, because I thought they had a right to life... uh, if you know what I mean? An embryo has a right to life, and a child has a right to life"

There are likely as many opinions on 'the right' to have children, (or if that right even exists), as there are on what constitutes adequate 'quality of life'. Mary Warnock in her book *Making Babies* suggests that "We must be aware of the danger of confusing what is passionately and deeply wanted with what is right...If something is regarded as a right you may come to feel less strongly about the thing itself, as you feel more strongly that you must get your due."[3] (p. 113). I don't entirely disagree with this principle however, I have discovered, as a psychotherapist that lack of choice in anything is a terrifying source of human discontent. I am also uncomfortable with a fertile majority making the procreative decisions for those suffering infertility. The construction of family in its various forms is a universal phenomenon which is significantly impacted by choice and *lack* of choice as well as the nebulous distinctions between desire and right. Science demands a stance of objectivity that I believe is rather akin to having respect for someone else's religion while quietly championing your own. It can be done but it certainly isn't easy which is why we place the checks and balance that we do on quantitative data and glare suspiciously at narrative presented as scientific research. Has either art or science earned the right to be the loudest voice?

When Robert Edwards first heard about the work of Patrick Steptoe he knew that he had come across the person who would help him get to the next phase in his research but, as Edwards told me in Washington, the divide between consultant and scientist was yet another obstacle to overcome.

"...*The thing about working with Steppie is, first of all, he was a damn bossy consultant, who would terrorize a room of women when he walked in, we knocked that out of him... we had to because he was a bully...I did learn they (consultants) could be bullies, they could come in and you almost had to get up and salute, you know this, it is the same in America. So what we had to do was to teach Patrick that we were equal, that science was now equal to medicine if not better than medicine because it was opening new corridors of knowledge about stem cells and the genome project that would dominate medicine."*

Medicine's breach of science does feel rather upper-class and Edwards rustic insistence on stripping away the mystery of life is not confined to embryology and in that, he is a human after my own heart. Edwards likes to poke at the status quo, maybe this is an obvious and necessary trait of an inquiring mind but according to Waddington: "The way man sees his material surrounding is by no means irrelevant to the way he sees himself"[2] (p.ix) When I asked Robert Edwards what the most important thing was he had discovered about himself" he was quick to tell me:

"Being stubborn. They always say about Yorkshiremen that they are not very intelligent but that they are bloody stubborn. I'm an example, a classic. The IQ usually ticks over gently and when the chap comes and starts beating me up I would smack him on the puss and carry on so it won't stop me, as the Pope couldn't stop me, and Patrick got stubborn too. He became stubborn and we had to keep on going together, I don't think any of us faltered, I don't think so, in the bad days, and there were some very bad days in Oldham when we couldn't get pregnancies, for three years we couldn't get pregnancies until we found, we think, what the reason was... a company had sent us a drug (artificial progestigen) which is supposed to save the luteal phase but we were getting all sorts of very short luteal phases.... It wasn't progestigen at all they had been wrong, we were transferring embryos to patients' and injecting them with an abortifascient and after 2-3 years I solved it... So this was, this was an example of how stubbornness helps, an IQ helps as well of course but it's not everything."

This story of persistence, as well as the vignette Edwards shared about the night he

and colleague Bobby Bannister had to climb over a locked gate to get into their Cambridge embryology lab, also reflects the tenacity that is needed to pursue infertility treatment. I was fascinated by the inexorable commitment it took for Robert Edwards to discover his eureka. His search for fertilization matched my own drive to conceive, down to his obsessive preoccupation with short luteal phases, the search for anything that would maintain embryonic support, and the absolute devastation and feeling of failure at the relentless onset of bleeding.

"We didn't do any immunoassays when we first started, we didn't have genes, immunoassays, or anything...I solved it by taking every lady who came in over the period of implantation and we started collecting blood day 4, 5, 6, 7, 8, 9, and we sent these to a very good friend in London who had the first immunoassay. I suspected we would see some delayed menstruation...we called these biochemical pregnancies (and that term is still used today)...and my colleague told me that 10 of our patients had very early pregnancies that disappeared and now I had my answer it was the damn drug...even if we knew what was going on we couldn't find the reason, so we had to keep coming back because there had to be another one (reason)..."

The non-stop hunt for 'another' reason defines the life of a scientist and as we came close to the end of our conversation Robert Edwards became excited about the latest research he was reviewing. Research that explores how salamanders can mend their limbs, research he believes might mean *"...that within twelve months people will be repairing human limbs, or human hearts, or human brains, what we call 'from within' just like the axolotls make their legs again, we won't use stem cells from outside."* This was fascinating to me. In our discussion the previous day we had talked about his early work on stem cells and later I revisited his prophetic words from 1980: *"Will we be able to discover how these cells appear and develop so regularly? Will we be able to extract the stem cells of various organs from the embryo...Will it ever be possible to use these cells to correct deficiencies in other human beings?"*[1] (p.186). Maybe all researchers, rather like stem cells, build upon the scaffolding that has been laid down by scientists who have come before but sometimes the world fails to appropriately recognize incontrovertible firsts, and Louise Brown is one of the world's incontrovertible first's.

Our eldest son was born at a time in IVF history when success rates from frozen embryo were little more than two percent. He is now a sophomore at Swarthmore College and plans to study medicine. Throughout his years at a Catholic High School he was often called to raise his own voice in support of assisted reproduction. His gratitude for life runs deep and traverses any boundaries between art, faith or science. When I look at him as a young man I continue to hold the memory of each plummet and fall on the road to his conception. However infertility was the fork in *my* road and in-vitro fertilization is now *his* legacy and story to remember.

In his book *A Matter of Life* Robert Edwards says: "...we have brought hope to thousands of couples and interest to millions of others watching from the sidelines" [1] (p.185). Hope is humanity's counterpoint to despair. Hope breeds imagination and crushes the lethargy that invades disappointed bones. Hope is a pledge to dig under rocks and lift heavy things. Hope is also inextricably linked to responsibility and Edwards accepts great accountability for his scientific work and for his patients. And when I ask him what he thinks of the possibility of winning a Nobel Prize he answers:

The last time we had a party at Bourn Hall, all the press arrived from around the world and I was there, Louise Brown was there and and Alistair (first frozen embryo pregnancy in Bourn Hall) was there. The mums were there; so we were all sitting together and the press said, "are you happy with Dr. Edwards, did he tell you everything so you weren't misguided?" It was a fair question and I knew my career was on the line. If they were going to say you never warned us, we were frightened of the dangers, you never told us the dangers, you

kept all things secret…they didn't tell us…but they got up and said, "we, we thank him because he told us everything and everything he told us has come true. He told us there may be a risk to have to check for anomaly but we sat down and discussed it as a family, and a little Scots boy was there and said, "…Ach aye, ach aye" (doing accent) he said, "what are you asking me that question for, that man over there he made me, what the 'ell can I say about him…" you know and everybody started laughing because of his accent and so that is what I think…

I think, in some profoundly trite way, it was all meant to be. Maybe science is really just that personal? I had fantasized my meeting with Robert Edwards as a transient union of vastly different minds (mostly mine under-reaching his), and had a vague aspiration that our hands might join. I considered myself one of the grateful patients from whom he has received hundreds of letters of thanks over the years (some of the best even ending up as doodle pads for his grandchildren).Yet in many ways his life is a dedication to my own; punctuated by points of immense surprise and disappointment, exaltation and loss. He is a man with a great spirit and a scientist looking to make sense of the world. He is a gift that has gifted many times over and on behalf of myself and others whose lives he has intersected, a most sincere thank you.

Liz O'Donnell, PhD is a psychotherapist in private practice in Cleveland, Ohio and specializes in infertility.

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1. *Edwards R, Steptoe P. A matter of life: The story of a medical breakthrough. 1980.*

2. *Waddington CH. Behind Appearance: A Study of the Relations between Painting and the Natural Sciences in this Century. First American Edition ed. Boston: MIT Press; 1970.*

3. *Warnock M. Making babies: Is there a right to have children? Oxford: Oxford University Press; 2002.*