

# Newsletter

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and Information Group

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## Dear Members and Readers


**L**ike this time last year, things are busy coming into place for the NISIG National Conference. We have some exciting speakers lined up, to address issues for people at all stages of their infertility journey. If you are not a member, contact us now to ensure you receive all the updates. More details on this page.

I hope you have been keeping up with all the media coverage that NISIG has been involved in! We have been very busy with both print and online media, as well as radio interviews, all helping to highlight the issues that affect us all. Thank you to the members who came forward in response to our appeal for people to share their stories, and especially to the men who were willing to go on the record. We print inside one of the responses we received to an article – thank you to the writer for permission to print it.

Since the AGM in April, members have been busy with two new NISIG subgroups – for donor conception and for surrogacy. The Donor Conception subgroup has been busy surveying members to plan activities and events. You can see the results of the survey on the website, and if you would like to connect with the subgroup, just let us know. The Surrogacy subgroup is also up and running, and currently has regular meetings in Portlaoise. Again, please contact us if you would like to be involved. Many thanks to the NISIG members who have been working hard to get these groups up and running.

Finally, I would just like to remind you all again to check with us in advance of attending any meetings. With the upcoming conference, we have again changed meeting dates in autumn. Keep an eye on the website, or send us a quick email if you would like to receive reminders.

I look forward to seeing you all on the 11th October



**Helen Browne**  
Co-founder and chairperson

**NISIG Conference**  
October 11th 2014  
Dublin Airport Hilton  
Hotel, 9.30am – 5pm

**N**ISIG is delighted to again be hosting a major conference, with an exciting line-up of clinicians and patient leaders from home and abroad. This presents a great opportunity to find out more about different treatments and diagnoses and the latest and most exciting developments. There will be immune issues, donor conception, personal perspectives and more.

You can book now at [www.eventbrite.ie/](http://www.eventbrite.ie/) - get your place before it is too late!

The full line up will shortly be available. If you are not on the NISIG mailing list, please send a quick email to [nisigireland@gmail.com](mailto:nisigireland@gmail.com), or check the website [www.nisig.ie](http://www.nisig.ie).

See you there!

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## 25 years of HARI and over 6000 babies!

**In 1989, in the grounds of the first maternity hospital in the world, Ireland opened its doors to the first IVF clinic in the country offering help and hope to all the couples in Ireland that were having difficulty having a baby.**

Professor Robert F Harrison, a man with vision, tenacity and determination, recognised the need for Irish couples to have assisted reproductive treatment. A consultant gynaecologist in St Patrick Dun's hospital in Dublin, he first attempted IVF in 1985 but the news was leaked to the press and a voluntary moratorium was called. Only after a contentious conference held in Maynooth on August 30th 1985, was he given permission to start an assisted reproduction service in Ireland.

One of the benefits of being the Master of the Rotunda Hospital was the accommodation provided in the grounds. In 1989, the Master chose to live elsewhere freeing up the brick house located near the Gate Theatre which seemed an eminently suitable and homely environment for those seeking treatment. This would become the HARI Unit. Following numerous extensions and upgrades, it now includes state of the art IVF facilities alongside the Royal College of Surgeons, Ireland (RCSI) Obstetrics and Gynaecology department.

Professor Harrison was always of the belief that the service shouldn't be just for those who could afford it and was instrumental in setting up the link with the general fertility clinic in the Rotunda Hospital and obtaining some funding to allow some people to have at least one attempt. The Rotunda Hospital support

of HARI also ensured that those seeking treatment had dependable access to facilities for full investigations, necessary surgery and any other therapies that might be needed to ensure that IVF was only offered when it was really needed. This is still HARI's philosophy today.

The stimulation methods, practices and technology have evolved very rapidly since those early days. The use of clomiphene citrate and the use of human Chorionic gonadotrophin (hCG) to control and time egg maturation was considered a huge advance many years ago but now with highly purified hormones available from drug companies and much better markers available for ovarian quality, stimulation protocols have become easier for the patient with better quality eggs being collected.

ICSI was introduced to HARI in 1996. The ability to work with very low sperm counts and injecting single sperm cells into eggs opened up the possibility for men to have their own biological children that otherwise may never have had this opportunity. To this day it is still an amazing technique, with tens of thousands of healthy babies born worldwide.

The ability to freeze and thaw sperm, eggs and embryos significantly improved the safety, effectiveness and cumulative pregnancy rate, saving women from



**Ciara Hughes**  
Laboratory Manager  
HARI – The National Fertility Centre

having to undergo ovarian stimulation. The first baby was born from a frozen embryo after treatment and thawing in 1999 - they called him Harry! The evolution of IVF treatment has been quite rapid. With the availability of commercially produced embryo culture media, the days are gone where the laboratory looked like a culture media production line when we used to make it in house. In those days we used to ask the women to donate blood samples to us so that we could add their serum to the media. Our women undergoing treatment and our nurses are very glad that that practice has long since passed.

We are privileged that our patients continue to trust us with their care in the hope of a successful outcome. For the natural desire of having a child, we should always strive to offer the best chance of success with the most natural solution. While the pace of scientific discovery is continuously increasing, with numerous new tests procedures and enhanced techniques, we must remember our duty to serve our patients to the best of our abilities with courtesy, professionalism and experience.

But most of all, we have to keep alive the mental exercise of placing ourselves in the patients' shoes and delivering the type of care we would expect. This HARI credo will continue for the next 25 years.



## Motherhoodwinked – One woman's infertility journey

As a young child, I was what many people would see as a typical little girl. My older sister would devise elaborate adventure games for us to play inspired by the Famous Five books and it would infuriate her that I preferred to play with my dolls instead. Whenever we did get around to playing Famous Five games I jumped at the opportunity to play Anne, my namesake and the stereotypical female character, who preferred cooking and cleaning to the adventures the others got up to. The truth was, I was at my happiest when I was alone playing at being a mother to my dolls.

Back then, aged nine, I thought that life was simple and that everyone could get married and have babies if they wanted to. Aged twenty-nine and newly married I still believed the same thing. Finding out that

this was not the case has been the hardest lesson of my life.

There were some early indicators that I might not be up to par reproductively. Aged fifteen, after months of mysterious, crippling stomach pains and bloating, I was finally diagnosed as having an ovarian cyst the size of a small orange on my right ovary. Being only fifteen, no one thought to talk to me about my fertility and how having such invasive surgery could potentially impact it due to scarring or damage to the ovary. At the time I was glad no one mentioned it, it would have been beyond embarrassing to talk about my fertility at fifteen. I was only just coming to terms with having periods and now I had to deal with ovulation as well.

Although my ovary was saved, so much of the tissue was damaged that it failed

to work again, but it was another fifteen years before I found that out. The years in between I spent on the pill, like most other young women, desperately trying not to get pregnant.

I remember a conversation I had with a group of friends when I was in my early twenties about having children. The talk had turned to IVF treatment, and whether or not we would consider it if we couldn't conceive naturally. Never one to sit on the fence, I stated to my friends, with resolve, that I wouldn't contemplate IVF under any circumstances.

I made that naive, ill-judged statement without any understanding or compassion for the pain and the heartache that infertility can cause, or the desperation that is felt with the realisation that you may never have your own biological child. My





Anne-Marie Scully

**Anne-Marie Scully is the author of *Motherhoodwinked - An Infertility Memoir* and *Five Million Born - An IVF Companion Guide*. Both are available to purchase on Amazon**

opinion was based on the assumption that IVF treatment was somewhat unnatural and unethical, and, therefore, certainly not for me. I felt sure that, were I unable to conceive naturally, I would accept my fate and get on with my life.

Just a few years after that conversation, newly married and bursting with the desire to be a mother, my husband and I found ourselves struggling to conceive. Initially I was positive; confident that we would get there eventually on account of our age. However, after almost two years of charting cycles, exhausting every old wives tale that proclaimed to aid fertility, and undergoing countless blood tests and internal scans, as well as taking various fertility drugs, IVF started to look like a very real possibility.

At first we could hardly bear to utter those three little letters; we could not accept that they were applicable to us. We were young. We were healthy. We had time. We repeated this mantra to ourselves every time the term crept into conversation, and it seemed to be creeping in more and more regularly. Looking back, our fear mainly stemmed from the fact that we were completely uneducated about what IVF entailed. We only really knew the horror stories: multiple births; women dying from overstimulated ovaries; unethical clinic practices. I remembered the comment I had made to my friends about accepting my fate and getting on with life, yet I couldn't seem to find a way to do that. Life without children just didn't seem like something I could ever accept, and yet IVF still felt too extreme to be the next step.

We were constantly reminded how lucky we were to have each other, a beautiful home, and secure, well-paid jobs. Given the harsh economic times Ireland was then entering, it seemed as though all of those things should have been enough for us, and we felt almost selfish wanting more when many around us had a lot less. The friends and family members in whom we confided never mentioned IVF as an option, and instead we were encouraged to wait. And wait. And wait.

*Looking back, our fear mainly stemmed from the fact that we were completely uneducated about what IVF entailed. We only really knew the horror stories: multiple births; women dying from overstimulated ovaries; unethical clinic practices.*

After two years of waiting, however, we were at our wits end. We felt as though our lives were on hold. We wished we could see the future, or that someone could tell us for sure that IVF would work for us. We were completely bogged down with the pressure of trying to make what seemed like such a huge, life-altering decision, and wondered how we would know when it was time stop hoping for a natural miracle and try IVF treatment. Was it supposed to be like falling in love – one day we would just wake up and 'know' the time was right?

I now believe that, regardless of age or whether you are part of a couple or single, making the mental leap towards accepting the need for IVF treatment is one of the major initial roadblocks. Since I had already made the 'decision', years previously, that IVF was not for me, I particularly struggled to accept that I was wrong and that it was something that I needed to consider, and was in fact prepared to undertake.

We ended up doing three cycles in very quick succession, all of them fresh since we never had any embryos to freeze. When the first one failed I was sure my heart was broken, when the second ended in a devastating miscarriage at eight weeks followed by a serious uterine infection and a string of other illness I felt completely beaten and unsure how I would ever move on. I had hoped that, over time, I might grow to accept that I might not be able to have my own biological child, and that I would be able to make a choice to stop treatment at a certain point. However, my desire to have a child only increased with every passing year; no matter how hard I tried to quench its flame, hope kept on burning.

I knew that our finances would eventually have a limit, but I didn't know if my head and my heart would also have limits. Money allowing, would I be willing to try every possible option? I wanted to be the kind of person who could accept my fate and move on without regrets, but I couldn't seem to make peace with that. Instead, I spent time researching advanced treatment options and reading about the experiences of patients who had tried. I found that there were many treatment options still open to me if IVF using our own gametes failed, including using donor eggs or sperm, donated embryos, or even surrogacy. Despite my fears that in the end nothing would work, and everything we tried would be in vain, I was prepared to keep on rolling the dice.

Our third cycle resulted in the birth of our daughter Grace in February 2014.

## Men need support too...

**Recent NISIG media articles have highlighted the need for men to reach out for support. NISIG received this response, which we print here, with the author's permission, to again urge men to seek help – do not suffer alone:**

I don't know really where to begin. I am 43 years old, married for 6 years to a lovely woman... We have been trying for a baby for 5 years but without success. We have tried one round of IVF in 2012 again without success. Over the past few months I have become so dreadfully saddened by the growing realisation that I may never become a Dad. I would have heretofore described myself a very positive person with a relatively happy disposition but over the past 6 months or so I have felt the joy of life draining out of me and now I guess I could only describe myself as depressed. I am constantly anxious, tearful, stressed, suffering sleeplessness, listlessness, withdrawing from social engagements with old friends, that sort of thing.

My wife would always have described me as bringing great energy to everything in the past. Now the fuel is running out. I've come to dread old favourite events such as Christmas or weddings. To my own ears (and my remaining logical self) I know this may come across selfish, and maybe paranoiac, but nevertheless these kinds of situations now sting me, even accentuate my own personal melancholy. To add further distress to the situation our infertility issues have more recently become a strain between the both of us, mainly around the urgency of us engaging in further IVF treatments.

I am not sure what point there is in writing this. How can the void in me be helped by talking or writing I ask myself. I read your article in the Irish Independent on the 13th June and while my own emotional (and sometimes physical) pain has not been lessened by it my sense of isolation was lifted a little by the thought that I did not suffer alone. Its focus on men provided some salve for wounds that I couldn't reveal anywhere else. There's a saying that goes "every cripple has their own way of walking". I feel like a cripple but with an invisible and profound disability. The disability of not being able to have children.

In a strange way not having a child is like bereavement. With death we mourn the loss of a person close to us and that time with them can be no more. With infertility I mourn the loss of someone who has never been and all the times with them that are never had.

Anyway I have been encouraged to ask for help so here I am.

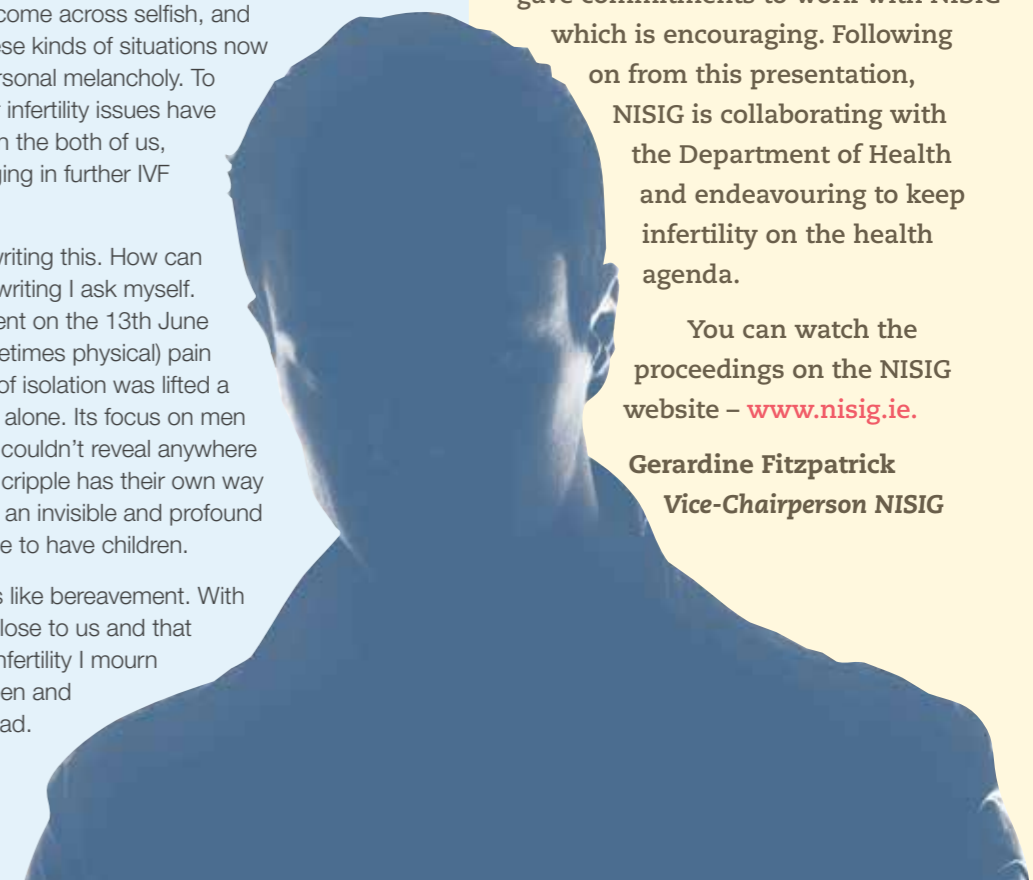
## NISIG makes presentation to Joint Committee on Health and Children

When the present government was elected it included infertility in its Programme for Government. NISIG set about seeking a meeting with Oireachtas members and, after almost two years, I was able to attend and make a presentation to the Joint Committee on Health and Children, on 3rd July 2014.

All the politicians present listened intently and acknowledged the Trojan work that NISIG undertakes on behalf of infertile people. Some politicians gave commitments to work with NISIG which is encouraging. Following on from this presentation, NISIG is collaborating with the Department of Health and endeavouring to keep infertility on the health agenda.

You can watch the proceedings on the NISIG website – [www.nisig.ie](http://www.nisig.ie).

**Gerardine Fitzpatrick**  
Vice-Chairperson NISIG





# Our Path to Parenthood

## A Member's Surrogacy Story

Our story begins with me sitting in the kitchen, hoping to grab a few precious minutes to write this piece as I listen to my husband inside the living room with our 7 month old baby daughter, patiently trying to keep her entertained with a ball and a few stories from a baby book. She is a full time job! At times, on our journey to parenthood, we thought that this busy domestic scene would never become a reality for us, but the one thing we never gave up on was hope!

We met when we were both that bit older. I don't think either of us could have settled for a life partner that did not feel right and for us that happened slightly after the prime age of our 20's or even early 30's. Quickly we realised that we would need IVF to achieve our goal of making a family. I had had some health issues requiring a few surgeries but I still did not believe that we would need any assistance other than straightforward IVF. The writing was on the wall however after multiple failed own egg/sperm IVF cycles in Ireland so we decided to pursue what we thought to be more advanced approaches abroad. Unfortunately, at two separate locations in Europe we were also unsuccessful.

I think it was after our 7th failed cycle that we sat down to do the maths... literally. Take out the variables and probable factors that are contributing to our failed results and do something different. I knew at this stage that we would need surrogacy to have any chance of having our baby.

We conducted the usual thorough scientific research that I do as a holder of a BSc (Science)! We didn't want to

take too many more chances as we were starting to get quite weary of the whole process. After an internet trawl lasting approximately 6 months, we had things narrowed down. Surrogacy in Ireland was not an option for us. We also discounted surrogacy in the UK or the US as these options did not suit our personal circumstances. We wanted an anonymous egg donor and a more flexible relationship with our surrogate. These were our main criteria in looking for a clinic. We had both separately spent some time in India in the past so were pretty familiar with that country and its people. The surrogacy process over there seemed to us to be the most straightforward for our needs and we started to look there.

We established contact with a number of couples who had had successful outcomes at a particular clinic in India. We felt assured after speaking with them that we were doing the right thing. We knew our options were now limited but that we had to pursue this path as we felt we would have regrets later on had we not. Our clinic came highly recommended and people spoke highly of the medical team and of their management of the whole surrogacy process. I have to add however that despite all of that, my faith in Mother Nature, albeit a very technological "Mother Nature", had taken a severe battering and I did not really expect to achieve a positive result.

It took approximately 8 months between contact with the clinic, review and signing of contracts, the egg donor becoming available and our selection of our surrogate, before we flew to India to begin the actual Surrogacy cycle.

I can tell you how we simply could not believe it when our surrogate tested positive for a pregnancy. We told absolutely nobody. Seven weeks into the pregnancy, our doctor phoned us to say there was trouble with the pregnancy and our surrogate had to be admitted to hospital with bleeding. We dared not breathe at that stage and believed the whole cycle to be over. We were so incredibly devastated but even at that stage we were most concerned about our surrogate. I think we both agreed to try to support each other through our loss. I really did not know how I was going to cope. I told my husband I would be okay but inside my heart I truly was questioning

*By now, we have forgotten all of that stress and only have the memories of a wonderful country full of life and bustle and of our beautiful surrogate with whom we remain in contact. We thank God for the people whose spirit, generosity and ingenuity gave us our magnificent, darling daughter.*

my ability to recover from this. Maybe a lit candle helped, or my endless prayers, but our surrogate got over the set back and the next scan showed a healthy and growing single live foetus.

After that scare, we could not take anything for granted. We never fully relaxed into thinking we were ever going



to hold our baby. But we did quietly work away at our respective jobs and we quietly prayed everything would work out! We received monthly ultrasounds and medical reports from our clinic. Eventually we were given a due date - a three week window during which our baby could be born at any time. We made our arrangements to fly to India. By this stage we had bought the necessary baby paraphernalia.

I have to say that the few weeks we spent in India before our baby was born ranks as one of the most stressful times of our lives. Life is so precious, and so precarious. We simply had no control over the end outcome - but we did have masses of paperwork, embassy visits, clinic visits, legal meetings, and meetings with our surrogate to attend to during that time and maybe that gave us a kind of a false sense of security into thinking yes, we do have some influence over the outcome and we can be busy at completing all of these tasks in the hope that we are somehow doing something to will our baby into existence. But to this day, I do still believe that there is that extra bit of magic needed to bring new life into the world.

Although we had both spent time in India, some of its cities are not for the faint hearted. But after a few days, we were well into the swing of things and we quickly adapted to the Indian way of life once again. Even though our hotel was very comfortable, and the clinic and hospital thoroughly modern, I, much to my husbands' chagrin, wanted to spend our free time getting to know the city better. My mother had requested I buy her a silk scarf to match an aubergine winter coat she had just bought. I think it was this simple task of looking for a specific scarf in all of India that saved my husband and me from going delirious with worry during those final weeks. We went absolutely everywhere, buying over 30 scarves just to find the right one. My Mum loves it now by the way!!!

We got the call to our hotel room at 4 am, the call that everyone on his journey wants to receive. "Congratulations, you are the parents of a beautiful new baby girl". The rest is history really. I mean it was equally stressful in the latter two weeks after she was born, to complete all the paperwork, meet more lawyers, sign endless more forms, do the DNA test, obtain our daughters' birth cert,

obtain her emergency travel cert, secure the FRRO exit visa, say goodbye to the medical team and to our surrogate, and all the while we had to cope with our little new baby in our hotel room.

By now, we have forgotten all of that stress and only have the memories of a wonderful country full of life and bustle and of our beautiful surrogate with whom we remain in contact. We thank God for the people whose spirit, generosity and ingenuity gave us our magnificent, darling daughter.

We would hope that other couples can be as fortunate as we were. There still remain many prejudices and misconceptions amongst Irish people about the path we took. We want to challenge those misconceptions. We want our daughter to grow up a proud Irish citizen but to be equally proud of her Indian heritage and proud of the way she came into this world. Our journey continues.

**Ciaran and Linda**



## The 33rd Evening Echo Women's Mini Marathon

**Y**ou still have time to register for the Evening Echo Women's Mini Marathon! You can enter online or in the Race Office, which will be open until Thursday 25th September. See full details of how to register at <http://www.eveningecho.ie/minimarathon/>.

The Mini Marathon will take place on Sunday 28th September at 1pm, and it offers a great opportunity to raise funds for NISIG. Please contact us for sponsorship cards, t-shirts and meeting times.



Don't forget that NISIG is now on Twitter. Follow us @nisig1 for the latest updates, news and events.



## Congratulations

Congratulations to  
Y on the birth of her son.

Congratulations to John  
and Caitriona on the birth  
of Luke.



## NISIG Meetings throughout Ireland

### Cork 2014–Support Meeting

**Venue:** SMA Parish Community Hall, Wilton, Cork  
*from 8pm–10pm*  
**Friday 3rd October**–informal meeting

### Dublin 2014–Support Meeting

**Venue:** Carmichael Centre, North Brunswick St., Dublin 7  
*from 10am–12pm*  
**Saturday 13th September**–informal meeting  
**Saturday 8th November**–informal meeting

### Surrogacy – Special Meeting

**Venue:** Portlaoise **Saturday 27th September** Please contact us for further details of this meeting

### Dublin 2014–Donor Conception Meeting

**Venue:** Dublin Airport Hilton Hotel  
*from 10am–12pm*  
**Saturday 22nd November**–informal meeting

### Limerick 2014–Support Meeting

**Venue:** Social Service Centre, Henry St., Limerick  
*from 8pm–10pm*  
**Friday 19th September**–informal meeting

Other meetings are arranged from time to time–please keep an eye on the website.

Please always let us know if you wish to attend meetings, as venues and dates can and do change.