

Finding light in the darkness: A journey through four miscarriages

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Keywords: *Miscarriage, multiple miscarriage, Repro-Immuno Deficiency, death, resilience, hope.*

Implications for practice

- Equip healthcare professionals, including reproductive endocrinologists, obstetricians and gynecologists, counselors, immunologists, mental health professionals, as well as organisations such as healthcare organisations and administrators, to enhance support for families facing challenges such as recurrent miscarriages and Repro-Immuno Deficiency.
- The Department of Health, the Department of Social Welfare and Development, and the Philippine Charity Sweepstakes Office advocate for personalised medical assistance. This approach focuses on addressing the emotional and physical needs of families, urging healthcare practitioners to play a crucial role in tailoring support to individual circumstances.
- Stress the importance of incorporating resilience-building strategies and determination into the medical support offered by healthcare professionals, including psychologists, mental health professionals, rehabilitation specialists, social workers, and health educators. Recognise their crucial role in empowering families facing complex medical conditions.

- Emphasise the potential for positive medical outcomes in the face of adversity, using examples of successful journeys to parenthood. Encourage healthcare practitioners to draw from such narratives when refining their medical support services for families encountering similar challenges.

Abstract

This paper explores the profound emotional and physical journey of a couple in The Philippines who faced the rare medical condition known as Repro-Immuno Deficiency (RID) while trying to conceive. The author and his wife endured the heartbreak of four miscarriages and the financial strain of various medical treatments, eventually leading to the birth of their fifth child. The paper discusses the emotional toll of repeated miscarriages, the challenges of accessing specialised medical care, and the financial burdens they encountered during their journey. It also highlights the support they received from a diverse network of individuals and the significance of their daughter as a symbol of hope and resilience.

Introduction

The loss of a loved one is a profound and indescribable pain that can shatter our hearts into countless pieces. But what happens when that anguish is multiplied not once, but two,

three, or even four times? The mere thought of enduring such an incomprehensible amount of loss is enough to bring even the strongest of us to tears.

Unfortunately, this has been our reality, our lived experience. Our journey to parenthood has been marked by anxiety and loss, with each pregnancy ending in devastating tragedy.

Our medical story

Preeclampsia affects 2 to 4% of all pregnancies and is responsible for around 46,000 maternal fatalities and 500,000 fetal or neonatal deaths each year (Magee *et al*, 2022). Due to preeclampsia, a life-threatening complication characterised by high blood pressure, our first child was born prematurely at just 28 weeks and 1 day weighing only 900 grams. Despite the excellent care provided in the Neonatal Intensive Care Unit (NICU), he passed away after only three days in 2010. Two years later, in 2012, we experienced a blighted ovum with our second pregnancy, followed by a miscarriage with our third pregnancy at just eight weeks for unknown reasons. Our fourth pregnancy in 2014 also ended in tragedy when we lost our baby at 12 weeks due to the baby's heartbeat suddenly stopping. Each loss has left us devastated, and we carry the weight of their absence with us every day. People often ask us questions like 'again?' 'Why?' 'What happened?' Questions which only add to our pain.

Pregnancy loss can be caused by five categories of immune problems in a couple which can lead to various health issues (Hunter, 2018):

- Category 1: Genetic compatibility issues
- Category 2: blood clotting problems
- Category 3: autoimmune responses
- Category 4: sperm antigen responses
- Category 5 immune cell increases.

Based on the laboratory results requested by our Repro-Immunologist, my wife has RID in categories 1, 2, & 5. To treat such illness, she had to undergo therapies (Lymphocyte Immunization Therapy or LIT, Intralipid and IVIG therapies). These therapies were not only physically exhausting but financially draining. LIT is a type of immune treatment that provides

hope for women that are suffering with unexplained recurrent miscarriage (Lymphocyte Immunization Therapy (LIT) For Recurrent Miscarriage, 2019). In our country at the time (2017), LIT procedure cost 25,000 pesos (approx \$350/£280) per session and we needed 4-6 sessions prior to pregnancy, depending on how my wife's body reacted. This does not include the doctors' fees.

During the procedure they extracted 14 vials of blood from me (as a donor) and processed it in the laboratory to separate the red blood cells from the white blood cells. These white blood cells, weighing about the size of a thumb, were then injected into my wife's skin. Aside from this, my wife had to take dozens of tablets and capsules of medicines every day (30 to 40) to manage her symptoms, and this increased once she became pregnant. In addition, we had to undergo Intralipid Infusion. As explained by our specialist, the intravenous lipids can increase the chance of successful embryo implantation and reduce the risk of miscarriage.

We also needed IVIG therapy. As explained to us, Intravenous immunoglobulins increase the number of live births in women with underlying immunological disorders and recurrent pregnancy loss. This cost us hundreds of thousands of pesos for just one session, and subsequently was needed on a monthly basis once we achieved pregnancy.

An emotional journey

Our journey with Repro-Immuno Deficiency (RID) has been a rollercoaster of emotions. Being one of the rare couples who suffer from this condition (according to our physician, 1 out of 200 couples is affected) we felt isolated and alone in our struggle. Our dreams of starting a family were shattered after multiple failed pregnancies, and we were left to deal with the heartbreaks and disappointments on our own.

At that time, doctors in our province were unfamiliar with RID, and it wasn't until after our third pregnancy that we decided to seek help from a Repro-Immunologist in Manila, Philippines. Our trips to Manila involved months to years of hospital hopping, with no guarantee of success. We felt like we were on a never-ending journey, searching for a glimmer of hope.

We then felt like guinea pigs, being experimented on by doctors who were still trying to understand this rare condition. We were emotionally and financially exhausted, but we kept pushing forward, hoping that one day we would be blessed with a child.

In addition to RID, my wife also has hypothyroidism, which poses risks to the baby in the womb. Therefore, she had to be treated before attempting to conceive.

We grew accustomed to enduring lengthy wait times of 2-4 hours to consult with our Obstetrics Gynecology Perinatologist. It is disheartening to see many others who have traveled from various parts of the country, coming from northern regions like us and as far as the Visayas and Mindanao regions, all waiting for our numbers to be called. One instance that stands out is the first time we consulted our doctor – we waited for 8 hours. We arrived at the clinic at 1pm and were number 38 in line. Unfortunately, the shortage of doctors who specialise in treating our specific condition has resulted in these frustratingly long wait times.

When we thought we could not handle any more stress, and just simply to get inner peace, we stopped all the therapies and put all things to God. We had lost hope and were ready to give up, but the thought of having a child gave us a new sense of purpose and reason to keep fighting. The good news of my wife's pregnancy was like a ray of light in the midst of our dark and despairing situation. Every moment was filled with anticipation and apprehension, wondering if our dream of having a child would come crashing down around us. Despite our joy at the news of my wife's fifth pregnancy, we were consumed by overwhelming fear and anxiety due to the knowledge of our slim chance of success – only 5% according to our repro-immunologist. The constant threat of RID taking our baby away from us at any moment loomed over us, with the uncertainty of when it might happen – possibly sooner, and hopefully not later. Our 5th baby's arrival caught us completely off guard, unprepared and struggling with expenses as we were then in the midst of constructing our new home. We were left with fear, anxiety, and uncertainty about what the future held for us.

And so, we gambled with our 5% chance. There is no assurance, but at least we tried. Our hearts were filled with an overwhelming mix

of emotions as we announced the arrival of the newest member of the family, baby Iris Gaia (IG). Due to Repro-Immuno Deficiency (RID), she was so small. I vividly recall our perinatologist and repro-immunologist repeatedly telling us, 'We'll just let the baby grow.' She had to stay in her mom's womb while the immune system of her mom was not attacking her (the baby) despite undergoing treatment. However, another problem arose: the umbilical cord was so thin that the nutrients the baby was supposed to receive were not enough. Unfortunately, preeclampsia surfaced again, and brain sparing began (as explained by our doctor). This is a situation where, instead of the baby getting nutrients from her mother, it is the mother who takes nutrients from the baby, and the baby's brain is highly affected.

Despite all the therapies and high-end technology, IG was so eager to see the world early! She was born prematurely at just 28 weeks and 1 day, weighing only 655 grams – just the size of my palm. We held our breath as we watched her fight in the NICU for every breath, her tiny body struggling just to stay alive.

IG is our fifth child, but she is the first to survive. Our minds can't help but drift back to the four precious angels we lost, and the pain of those losses still lingers on us. We often wonder how we could endure such heartbreak, yet we must find the strength to carry on because IG needs our support.

Challenges faced: Financial and emotional struggles

Thankfully, IG is a fighter. Despite her very small size, she exuded a strength and resilience that is simply awe-inspiring. We are grateful for the outpouring of love, support, and prayers that have come from people from all walks of life. We know that it is because of these people that IG is with us today.

We struggled to raise funds for IG's medical expenses during her NICU days. Due to financial difficulties, we had to move her from St. Luke's Medical Center (SLMC) at Taguig to the Philippine General Hospital (PGH) in Manila and then to Angeles University Medical Center (AUFMC) in Angeles City, Pampanga. The cost was staggering – we needed PhP 40,000 to 70,000 pesos (approx \$710-\$1240/£560-£990) per day

just for her hospital bill alone, and that didn't even include the professional fees of the team of neonatologists in charge of her, which were PhP 50,000 pesos per week (approx \$890/£700). Her lead neonatologist informed us that IG would need to remain in the hospital for another 1 and a half months until she stabilised before we could move her to a much cheaper hospital.

For 31 days we slept in the lobby of St. Lukes Medical Hospital, especially my wife. I traveled almost every day from Pampanga to Taguig just to give peace of mind to my wife. That is about 2 to 3 hours travel everyday including traffic jams.

We are beyond grateful for the care that we received at St Luke's Medical Hospital. They possess the high caliber and state-of-the-art technologies necessary to care for a preterm baby and her mother's case, but we simply could not afford the bills in this hospital. We were forced to transfer her to the Philippine General Hospital (PGH), a government hospital. However, since she was more than a month old, IG was not allowed to be with the other NICU babies. PGH installed a private NICU room for IG, for which we paid on a daily basis.

After another month we were so exhausted and drained physically, emotionally, and most especially financially that we decided to move IG to the Angeles University Foundation (AUFMC). Doctors did not want her to be discharged, but we chose to. We signed a waiver and we gambled again, our last resort... we thought if she is at AUFMC, we know the people there. We can somehow or probably make promissory letter if we cannot pay our hospital bill because we work there. We believed that being in our company would allow us to talk to our co-employees, and, most importantly, we could hug many of our relatives and friends to get emotional support. We just said, *bahala na...* ('Let it be...').

Finding light in the darkness: Support and generosity of others

It was then a few months before Christmas, and Iris Gaia was given a chance to see the beauty of life. After 78 days in NICU, we were finally sent home with IG. It was the perfect Christmas gift for us as parents and everyone else who loves our family.

During that difficult time, we saw God in the

faces of different people, and encountered the kindness of countless individuals who helped us along the way. From our own relatives, friends, colleagues, students and their parents, former students, to strangers and members of the Angeles University Foundation Family, as well as individuals from various schools across the Philippines. Even entertainers like Yaya Dub Maine Mendoza and Kierwin King (who happened to be my former advisee) helped bring awareness to our situation. We also received aid from unexpected sources such as mountain climbers, fraternities, vendors, jeepney drivers, public school teachers, Parents Teachers Association of AUF-Integrated School, anonymous doctors who paid for our one-day medical bills, politicians, laypeople, churches and various government organisations such as Local Government Units (LGUs), Philippine Charity Sweepstake Office (PCSO), and Department of Social Welfare and Development office (DSWD). The list goes on, and we remain forever grateful to these diverse individuals who extended their support and assistance during our time of need.

How can I ever erase from my memory the moment of counting donations? As I separated the money from the envelope, my happiness shattered as I unintentionally tore (divided into two) the check given by the university president, which contained a large amount of money. I wept and blamed myself for the foolish mistake I had made. The weight of what transpired kept me awake throughout the night. Then, perhaps as a stroke of fortune or divine intervention, God reminded me of a friend – a bank manager. With a heavy heart I shared my predicament. With kindness, my friend endorsed me to a bank manager at the bank where the check was named, and there the check was cashed.

Betrayal

Behind all these struggles, it's heartbreaking to know that even in our weakest and most vulnerable moments, there were those who would take advantage of our struggles. Despite our financial difficulties being known to many, one woman preyed on our weaknesses. She took advantage of IG's condition and deceived her friends, former classmates, teachers, and people from social media into giving her alms for IG, collecting a total of approximately 300,000.00 pesos (approx \$5330/£4220). Regrettably, not a

single centavo of the money she collected ever made it to us. It's a betrayal of trust that wounds us deeply.

Becoming stronger

The experiences tore our hearts into countless pieces, leaving us feeling overwhelmed and uncertain about our fate. We drew upon our inner strength and endurance to persevere through our pain and find hope for the future. We gain empathy and support from others who have shared similar experiences, and because of our struggles, we become much stronger and more compassionate individuals.

Now, after all the sacrifices we have Iris Gaia. A proof that God is with us. Every day, and given the chance, I will always share with people how God is alive through different faces. I always express our deepest appreciation to everyone who has supported us during our trying times. The love, encouragement, and the generosity of different people have been our lifeline.

I am forever grateful for the profound impact these people have had on our journey. Within the very depths of my heart, I hold a treasure named Iris Gaia, a precious gift of love bestowed upon us by people of different walks of life. The very essence of her name intertwines the beauty of the existence of people representing the ethereal magnificence of a rainbow (Iris means rainbow) and the grounding presence of the earth (Gaia means earth). She is a radiant beacon of light and hope who gives color to our world.

Conclusion

We encountered Repro-Immuno Deficiency due to genetic compatibility issues, blood clotting problems, and immune cell increases.

Undergoing intensive therapies like Lymphocyte Immunization Therapy (LIT), Intralipid Infusion, and IVIG therapy proved to be both physically demanding and financially draining. The LIT procedure, involving blood extraction, white blood cell separation, and injection into my wife's skin, offered hope for a healthy pregnancy. Intralipid Infusion and IVIG therapy improved embryo implantation chances, reduced miscarriage risks, and addressed underlying immunological disorders.

While the financial burden was significant, the potential for a successful pregnancy made every sacrifice worthwhile. Despite feeling isolated and alone, we persevered through the wisdom and recommendations of our medical team, ultimately witnessing the success of a pregnancy. Our journey stands as a testament to the power of resilience, the importance of seeking specialised care, and the indomitable spirit that propels individuals forward despite the most challenging obstacles.

References

- Lymphocyte Immunization Therapy (LIT) For Recurrent Miscarriage* (2019, May 2) The Fertility & Gynaecology Academy. Available at: <https://www.fertility-academy.co.uk/blog/lymphocyte-immunization-therapy-lit-recurrent-miscarriage/> [accessed September 11, 2023].
- Hunter A (2018) *Reproductive immunology - What is it and how to treat* Available at: <https://dralisonhunter.com/treatable-conditions/reproductive-immunology/> [accessed November 16, 2023].
- Magee LA, Nicolaides KH & von Dadelszen P (2022) Preeclampsia. *The New England Journal of Medicine*, 386, 1817-1832. <https://doi.org/10.1056/NEJMra2109523> ■