

Management Committee Report

Today I resign my position as National President of the Reflux Infants Support Association (RISA) Inc. I have been honoured to hold this position for five years and in that time I've had visibility of the way this condition (and paediatric gastroenterology generally) is handled. And because I am departing and my words are no longer reflective of an organisation who wishes to be closely aligned to and always work constructively with the medical profession, it's time for me to say **my piece**. This is my view. Not RISA's. But it is an informed one, I promise.

It usually falls to me at this time of year to tell you how wonderfully RISA is doing. And it is. It always does. On the smell of an oily rag through the blood, sweat, tears, vomit, poo, snot and insomnia of the most beautiful group of people who selflessly give, as only the incredibly traumatised can, to a cause that is dear to their hearts – because it nearly broke them – or it is still trying to.

So I'll fill in the blanks of the wonderful work these ladies (and the occasional bloke) have done a bit later.

For the moment I want to say I HAVE HAD ENOUGH. On behalf of all of our 1100 members, I HAVE HAD A GUTFUL. LITERALLY. The understanding of paediatric gastroenterology across this country is appalling – particularly across the medical profession.

I am sick to death of hearing from every second GP in the country that infant reflux doesn't exist. It's like trying to argue that the earth is flat. How many endoscopy pictures do you need to be sent to you to convince you? How many ulcerated oesophaguses does it take?

And as for the fallacy that reflux medications like proton pump inhibitors don't work, BITE ME!!

Here's the thing. All the studies say that the meds don't work ON BABIES WHO DON'T HAVE REFLUX. (Thanks for that!)

NEWSFLASH GENIUSES: THEY DO WORK ON THE BABIES WHO DO HAVE REFLUX.

Just ask any paediatric gastroenterologist in the world. So perhaps it would be helpful if our diagnostic criteria provided to doctors and hospital staff reflected that. Here are just some of the problems:

- They are all full of statements about who the meds don't work on. (Yep, those that don't have it).
- Moreover, they say that kids who don't vomit don't have reflux. WRONG. Flat out wrong. Silent reflux is real.
- They say that kids who are gaining weight don't have reflux. WRONG. Again, how many endoscopy pictures of babies of good weight who are burned from bottom to breakfast would you like?

For all of these scenarios I can send you endoscopy pictures to prove the point. So because THE GUIDELINES ARE WRONG or just downright misleading, the doctors don't believe the parents. It's a flat out joke.

Now how hard to you think it might be to work out how many of these babies DO in fact have reflux? Well the diagnostics can be a bit tricky but do you think if we assumed that the medications worked on the baby then the baby probably has it? Or at least whatever it is that

the baby has (even if it's not reflux) responds to reflux meds. On that basis, maybe we should just pull the figures on how many babies are being prescribed it more than once. (ie it worked the first time so we'll keep going.) But that might belie the dogma that it doesn't exist mightn't it?

But wait for it. Apparently we don't collect the numbers. We certainly don't collect the age of the children these medications are being prescribed. We don't collect how often its being prescribed off-label. And we don't collect the data on how often medications in this category that have not been approved for use on children are being prescribed or at what dosage. So many problems with all of that.

But we know that the prescription rate is high because there is concern about the prescription rate being high. But where is the level of concern for **why** the prescription rate is high? Why are doctors (who actually listen to their patients) prescribing these medications?

I know the general consensus is to say that they are prescribed because the parents want them to be prescribed. I think that neither parents nor doctors are that irresponsible in the majority of cases. Sure parents are desperate if they are wanting to medicate their babies. So they try it with the consent of the doctor and if it doesn't work they stop, right? So how many stop and how many don't? The reality is they are being prescribed because they are needed in a greater and greater number of cases.

How many cases? We don't know. Certainly the number of RISA members, facebook followers and website visitors is growing. As is the number of online groups out there without any insurance or guidelines preventing them from providing pseudo-medical advice or protecting the welfare of mothers and babies (unlike RISA).

Here's the kicker. We now know from our recent study that both babies and parents are at greatly increased risk of harm from the misdiagnosis, under-diagnosis and delayed diagnosis of reflux in infancy. **In 75% of cases people are sleeping their babies upright.** Not on their tummies or on their sides in a recovery position like you might for an adult who is at risk of aspiration (remember the recovery position you were taught when you did first aid at school?) Not because they are unaware of SIDS advice, **because they have no other choice.** It is simply not possible to hold a baby upright for 24 hours a day, 7 days a week for a year. And because everyone is so frightened of being sued, we're not having a risk-management based conversation about it in case the message gets mixed. Really? We're all that stupid are we?

Is it safer to sleep a baby on its side in the recovery position or fall asleep holding it upright in a chair where it can fall down and suffocate? Risk minimisation. Something that can be discussed with a sensible GP if sensible guidelines were allowed to be discussed. But they can't. Because we're all too frightened of our own shadow.

This whole area is full of intrinsically stupid contradictions. We can't possibly do appropriate research on babies. All of the hoops that have to be jumped through in paediatric research are prohibitive. The money isn't there. We have to be careful researching babies. I get that there are ethics involved. But where are the ethics of prescribing off label meds in untested doses on tiny babies? Too hard to do the research, but easy enough to prescribe without knowing the consequences. Where are the ethics in that? But that is happening because those at the coal face are desperate to help these babies. I'm grateful for the irony – but it's a serious problem for health policy makers.

Possibly some slightly more inventive thought needs to be put into the problem rather than blaming mothers (and fathers) for imagining it. Perhaps there's a (shock horror) CAUSE for the increase in this bloody awful disease in children other than the presumed collective neuroses of parents who lack fortitude.

Why are they being born with looser internal organs that can't keep acid where it should be? Why are they producing so much acid? What has happened to the gastro systems of our species that more babies are being born so acidic that they can be vomiting blood and acid almost straight out of the gate? The microbiome? Gut bacteria? Faecal transplants? It's all happening (elsewhere in the medical community) – it's the forefront of immunological thought. BUT NOT FOR BABIES. Not even for kids.

We have to be extra careful with kids. That is, if by "careful" you mean ignore them.

Kids need a higher standard. Not NO FREAKING STANDARD.

This organisation needs support. RISA needs to be funded. It is a national organisation with a clinical focus (ie that stuff that we deal with is dealt with mainly at a state health level) but it's a national problem. Currently we have 1100 members. 175 joined in the last year. Many more joined free groups. From what we know from our survey that means that 130 (75%) of them are sleeping their babies upright right now. Tonight. 51 (29%) will have a diagnosis of PND or anxiety. A further 42(24%) will self-report having had those symptoms but won't have sought help. You don't have to be Einstein to work out that exhausted parents and inconsolably shrieking infants are not a good mix.

And if you're not motivated by heartstrings, have a think about the cold hard dollars being poured down the drain. Each of them are multiple presentations to emergency departments. Each of them are seeing GPs almost weekly. They are under multiple specialists. They are on medications. Prescription formulae. And they are the kids who will very often turn out to have a whole heap of comorbidities that could have been identified early. Much of that cost could be averted. It's just waste. A bit of appropriate research, a review of existing figures, a small education campaign to medical professionals about what to look out for and how to best help these families and you've saved millions. And very likely a few lives along the way. The cost to the system of this systemic neglect is staggering. Just staggering.

If you don't look for it, you'll never find it.

The irony is we have this federal funding system for hospitals and health care providers that relies on them incorporating feedback. But they only get answers to the questions they want to ask.

No one is asking about specific conditions and how best to treat them. I'm here to tell you that the rise and rise of chronic disease is starting from birth and it starts with these kids.

Who is asking the other organisations like ours what could be done to best help their kids. Odds-on many of the things they would be asking for, like us, would actually SAVE GOVERNMENT MONEY if anyone dared to listen.

SO IS ANYBODY LISTENING?!?

This is thousands and thousands of families across the country. I'd put money on almost everyone knowing one of them in their close circle. There's more than anyone wants to admit.

There'll be a few in the parliament, I'm sure of it. Why are we not talking about it?

WE'RE OVER HERE!!! THIS IS THE 'TOO HARD BASKET' HOPING SOMEONE WILL GIVE US THE TIME OF DAY. ANYONE?

For my fellow executive members, I have to say thank you for the enormous privilege it has been to be president of the organisation for the past five years. You are all amazing women. Truly amazing. You all have incredibly difficult challenges in managing some of the sickest babies I know and I am in awe of you all daily. I often wonder why it is that some of the people with the sickest kids have the most passion to dedicate to help running this organisation.

In particular this year I need to thank Gabi, Maddy and Susan for doing most of the actual running of the organisation. The wheels would absolutely have fallen off without you all and I can't thank you enough. The first two have had so many hospital admissions for either themselves or their children that I actually can't believe they are even upright much less holding this organisation.

I also want to single out a few members of our welfare team – Kate and CY in particular – for all of the heavy lifting they have done in making sure that some of our most vulnerable people are well looked after. There are of course more people on welfare doing the same work but there have been very difficult things to manage in the past year and I am in awe of how incredibly professionally they have been managed.

And lastly, but in no means leastly, I need to thank Sarah Auld. The survey and research analysis that went into "The Reflux Rollercoaster: Dismissal, Delay and the Cost to Families and the Health System" is an amazing document. It was an unwieldy beast to pull together. But it was tamed beautifully by Sarah. She threw her heart and soul into it and it just wouldn't have happened without her. I also need to again thank CY for the huge amount of work she put into it – particularly the analysis – while heavily pregnant.

As for the usual nuts and bolts – the evidence of how much heavy lifting this organisation does – have a look at this:

- 310,000 visitors to the site – 14% more than last year and 350% increase on 4 years ago
- Overwhelmingly the users of our site are 25-34 year old women
- Our most popular content is far and away our information about what reflux is and how to manage it
- We have more than 11,000 page likes on facebook – an increase of 25% on last year
- We have 1100 members, a 15% increase on last year.

The reality is though that much of the support we provide online can be obtained elsewhere at no cost. There is no membership fee. And essentially what that fee buys you is the quality of support and advice. Our members operate under rules whereby we don't offer medical advice. We don't swap dosages. We support and encourage. We swap management tips and we try to help each other through. But these days, with facebook groups and social media groups proliferating, RISA's funding source is essentially under threat.

Thought will need to be given to other revenue streams going forward.

I remain insanely proud of this organisation. I step down to make way for someone else a little less tired and cranky than I've become. But I will never be too far away. These are the women who supported me through some of the toughest times in my life and I have made lifelong friends here.

Keep up the good fight.

Joanne Matthews
Outgoing President
Reflux Infants Support Association Inc
July 2017.