

## TEENAGE MEMBERS' EXPERIENCES OF PREMATURE OVARIAN INSUFFICIENCY (POI)

### Introduction

POI affects one in 10,000 women under 20.

For women who have been diagnosed with POI as a teenager, it can often have taken a considerable time for the diagnosis to be made and furthermore, being unable to establish a clear cause for POI can be frustrating and difficult to accept.

Here are the stories of three of our young members:

### Gillian's Story

I was 11 when I had my first and only period.

My GP insisted that there was nothing to worry about and said to return for tests when I was 16 if my periods had not returned by then.

From 16 onwards I had test after test, one trip after another to the hospital and all the doctors remaining tight-lipped, with no explanation as to why I did not have any periods.

"Have I had an early menopause?"

Checking my notes, she said "yes" but as a precaution I was to be sent to the hospital for yet another check-up. Yes, I had had an early menopause, probably in my early teens. I was only 25 and felt as though my body had betrayed me. I suddenly felt 55. No periods, no night sweats, no mood swings or vaginal dryness. No symptoms! But I was told I had to take HRT to protect my bones and heart because I was so young. Immediately I felt like a pill-popping junkie and my moods would suddenly swing from sky high to rock bottom for no reason. My weight started to climb and I was very unhappy; it made me feel even older. I was constantly weepy and felt so sorry for myself, and I couldn't help it.

I felt a failure, useless as a woman, as I was unable to conceive naturally. I knew the chances for having a child would be limited because of the severe shortage of egg donors at present. The waiting list is in excess of five years for anonymous donors where I live. Just another disappointment when you are already down.

In the meantime I keep trying different HRTs. Hopefully I will find one that suits me soon. That's the battle because every one is different.

My husband's understanding and love has kept me sane and The Daisy Network has been invaluable for support and information...

Thank you!!!!

*Gillian*

## Stephanie's Story

At the age of 11, my periods were erratic: by the time I had reached 16, they had stopped. I put it down to the trauma of my dad's death and thought that they would start up again.

I carried on at school, finishing one childcare course to go onto another at college. I didn't worry that I might never get pregnant naturally. I just thought that having erratic periods was the way the body was meant to be.

Eventually I had an appointment at my local hospital with a gynaecologist for an abdominal scan.

It still hadn't entered my head that I might never have children so I wasn't at all prepared for the shock I received when I heard the results.

Neither my mother nor I had even sat down before the gynaecologist bluntly told us that it looked like I would never have children. I was so shocked; I didn't know how to feel. I thought, "This can't be happening to me, I'm only 17."

We were told that one of my ovaries was missing and the doctor said she could refer me to a hospital in London but they would only tell me the same thing.

The gynaecologist wasn't at all sensitive in the way she spoke to us and she didn't appear interested in any questions we wanted to ask.

Now it seems a long time since my first appointment at the Middlesex Hospital, where I had another abdominal scan. This showed that I have both my ovaries but they are very small. I had numerous blood tests to check my oestrogen, FSH and LH levels and a bone density scan.

I was examined by a doctor and told that I hadn't developed properly but most people see me as someone who is thin and finds it hard to put on weight. Hearing this wasn't hard to accept but what followed was and still is.

The results of my tests showed that I had premature ovarian failure. I was going through the menopause and would have to take HRT to get the hormones my body needs and to prevent osteoporosis. I was only 19, not 49, and thought that they must have got it wrong.

I had always thought the menopause was something women went through from 45 onwards, not at my age. Now that I am a member of The Daisy Network, I realise that it is happening to more and more women of my age.

The most frustrating thing is that they couldn't, and still can't, give me a reason as to why this is happening to me. If I was given a reason, then I might be able to accept it even though I am only 25.

Although I became clinically depressed and had to take anti-depressants for a few years, I never changed my mind about a career in childcare.

I am glad about that because being around children sometimes helps me to put the thought of never getting pregnant naturally or never having children, to the back of my mind.

I went onto HRT and tried three types over four years before deciding to come off it in January 1999.

I wanted to see if I would bleed every month without it. I did carry on bleeding slightly every two months for a few days - it wasn't like a proper period. Each time I would get my hopes up that my body was sorting itself out, especially one month when I actually had a proper period. I haven't seen a sign of anything since December 1999. So the hope that I am a normal 25-year-old whose body has cheated its way out of POF isn't a realistic one.

Since going through this, I have gone on to do my NNEB and am now a learning support worker for special needs children and I really enjoy it.

Before this I was a nanny in Florida for a special needs boy. We used to have a great time together, going for walks and swimming in the local pool. Mealtimes would involve having to

watch Teletubbies and at bedtime I would read him a story. I used to wonder if all the enjoyment we had together I would one day be able to feel with my own child.

It was during this time that I decided to come off HRT and for now I think that it was the right choice. I don't feel anywhere near as moody as I did whilst taking it or so negative about myself.

My self-esteem has slowly built back up, although I still get off-days and think "why me?" especially at the beginning of the month when it can feel like I've got PMT. I am not as tired or as fed up as I used to be - which is good.

I am now taking a calcium supplement, evening primrose oil and a herbal supplement, along with Evista which is a designer oestrogen tablet, which mimics the effects of oestrogen to help prevent osteoporosis. I have to see Dr Conway at the Middlesex Hospital every year and he thinks that I may have to start oestrogen again if my bones start weakening. If this happens, I hope that it won't be for a long time yet! I have a bone density scan every two years to keep an eye on this.

The only problem that I have noticed now I am off HRT is how much I ache all over and, even though I'm not sure if it's all connected, I have reflexology and aromatherapy every now and then which seems to be helping.

As much as I wish I wasn't going through the menopause, I think that it is a small price to pay when I think about the little boy in Florida and his problems.

It makes me realise how lucky I am to have a life where I can do things for myself without having to rely on others to help me, as he may always have to do.

*Stephanie*

### **Charlotte's Story**

Hi, my name is Charlotte. I am 20 years old. I am going through premature menopause. This is my story.

I was a happy teenager going through the usual puberty stuff. Then my periods stopped at the age of 14. So I went to the doctor. The first thing the doctor suggested was for me to have a pregnancy test to see if I was pregnant. And I knew I was not pregnant!

It carried on for months — still no period. The doctor finally decided to send me to see a gynaecologist to see if he could find out what was wrong with me.

Deep down I knew something was wrong and that I probably would not be able to have children.

After lots of tests, the gynaecologist finally told me the reason why I was not having any periods.

He told me I was going through a premature menopause. I could not believe it. I had never heard of young people going through the menopause at my age. The first thing I asked the gynaecologist was would I be able to have children? He told me that he believed in miracles. It's so funny now because, when I think of what he said, I think of the song 'I Believe in Miracles' by Hot Chocolate, which makes me laugh.

My mother was not with me when I was diagnosed and when I told her she could not believe it and she wanted to know why. My mother wanted to know what had caused it and the doctor told her it could be passed down through the genes or an illness could have killed off my eggs.

Of course, when I look back, I was having hot flushes and thinking that I was just hot. My mum was having them at the same time so I knew that she was going through the menopause.

It has been over four years now since I was diagnosed and you do learn to come to terms with it. I do have my good days and my bad days but who doesn't?

Earlier this year I was in hospital because I had gallstones and they had to remove the gallstones and my gall bladder. The way I look at things now is, "So, what is going to happen this year?" I have had so much bad health since the age of 14, starting with glandular fever, shingles, numerous colds etc. I was told the gallstones could have been due to taking HRT or because of my weight fluctuating.

I am very sad that I am unable to have children, especially as when my friends discuss the subject I feel left out. A close friend of mine recently had a baby so I am trying to enjoy her baby and she has asked me to be godmother. I feel there is a great void in my life and there is nothing to take its place.

If I were career-minded, it would not be so bad – but all I have ever wanted is to be a housewife and mother. But life goes on and I just get on with it. One thing I find that does help is talking about it.

I am hoping eventually to be able to have IVF treatment.

*Charlotte*

**Any medical information in this fact sheet is for guidance only. The Daisy Network and its members have produced this fact sheet and we cannot guarantee its medical accuracy.**