

## **A Brief Introduction to some of the NSW YAWA Group Members**

### **ELAINE, aged 36, has Ankylosing Spondylitis (AS)**

Current Medications: Prednisone (other medications on hold while breastfeeding)

NSWYAWA Co-Secretary

---

Was originally misdiagnosed at age 13 (1981) with bursitis, finally finding out it was AS in 1991. Tried alternative treatments after a rheumatologist frightened the daylight out of her, saying she had to have a knee operation and go on tablets that would make her sterile (at age 23 that wasn't what she wanted to hear). Finally in 1999, went to a different rheumatologist under pressure from worried family and was put onto Methotrexate and Plaquenil. Felt fantastic after being in pain for years.

Had to have a left knee replacement in 2002 (aged 34) - best thing she could have ever done! Elaine is married to Peter and is having her first child in June 2004, which she couldn't have done without the TKR (Total Knee Replacement) and great treatment from her rheumy.

Main health issues from AS have been fusing and damage to left knee, both elbows, and some other peripheral joints, and uveitis (left eye).

Went off medication in late 2003 to have a child and gave birth to a daughter in July 2004.

### **LEANNE, aged 29, has (Juvenile) Rheumatoid Arthritis (RA)**

Current Medications: Enbrel (25mg twice weekly), oral Methotrexate (25mg weekly), Celebrex (400mg daily) and Prednisone (7.5mg daily) plus Tramal SR (200mg daily) for pain and medication for high Blood Pressure (due to RA meds).

NSW YAWA Co-Chairperson, NSW YAWA Co-Founder and Web Admin

---

I was diagnosed in 1983 (aged 8) with systemic onset JRA. I am and have always been Rheumatoid Factor (RF) negative but I presented with the classic symptoms of pain, stiffness and inflammation in many joints, fatigue, high fevers and a salmon coloured rash. I had a number of joints involved right from the beginning and one thing I clearly remember is that the pain was worse in different joints each day and if it was a joint on the left side of my body one day, it was likely to be a joint on the right side the next.

While many people offer me pity for being diagnosed so young, in many ways I am one of the lucky ones because my diagnosis occurred fairly quickly due to my parents having an awareness of the disease (my dad's cousin also has JRA). Also, because I was fairly young, I don't really remember a life without RA and I didn't go through that period of having to face potentially giving up things you loved to do.

My initial treatment was with high dose aspirin and I have had one period of total remission for just over 2 years (1988-90). But since then, each flare and good period is worse than the one before. On the plus side, while I do have an unstable left collar bone joint and other minor joint changes, I have no obvious or major deformities.

In the past 20 years, I have tried almost all available conventional and alternative / complimentary treatments. In recent years, this has included Methotrexate Injections, Arava, Cyclosporin, Remicade, Naprosyn and Fish Oil supplements. On average, each medication lasts 2 years (but recently it has been more like 6 months) although I have been on methotrexate for about 10 years and took Naprosyn for about 15 years.

I have won awards in gem cutting, completed a university degree, work full time and have travelled domestically and internationally. I married Martin in September 2001 and we purchased our first home in September 2003. We hope to start a family in the next few years (arthritis willing).

---

**MARK, aged 22, has Juvenile Chronic Arthritis (JCA)**

Current Medications: Arava (20mg daily), Voltaren (50mg twice daily) and Prednisone (5mg daily). I also take Caltrate (600mg daily), Catapres (100mcg) for sleeping, Actonel (30mg weekly) for my bones and Fish Oil supplements twice a day.

---

I was diagnosed in 1990 (aged 8) after I began having problems liking holding my pencil at school. Over the years, I have had numerous flares and issues and have tried various medications including Salazapyrin, Methotrexate injections and tablets (but both were making me that sick I could not take it anymore) and Thalidomide. Towards the end of my first year of High School, a sprained ankle that wouldn't heal lead to x-rays and a full body scan. These revealed numerous potential "hotspots" of arthritis activity. When I was 16 or 17, I needed to be hospitalised for intensive treatment to try and get me back on track. Then from October 2003 until April 2004, I underwent 2 operations and a lengthy period in a cast to fuse my right knee (my surgeon felt this was a better option than a knee replacement given my age).

I have completed my HSC and a number of TAFE courses and am about to start a Barman's course (at TAFE). I enjoy knitting and have made a number of items. I am currently knitting a blanket that is my own design (made up of numerous squares), a jumper and a dog blanket and I am about to start on a pair of socks. I also enjoy reading and listening to music and plan on taking up Lawn Bowls again in July 2004 (I started it in 2003 but had to stop due to my knee problems).

---

**MICHELLE, aged 33, has Osteo Arthritis (OA)**

Current Medications: 1 x 200mg Celebrex when needed, and Capadex for when Celebrex fails.

---

I was originally misdiagnosed at age 13 with growing pains that just went on, and on and on for years because I had one leg slightly shorter than another (still like that to this day). I still remember the first onset of my deterioration - this pain I can only describe as akin to childbirth pain - it fades from your memory until it strikes again months/ years later in a "take the breath away" moment. I also distinctly remember my pain's onset, which brought me to tears after excessive walking (sorry read shopping - that's what I was doing). I went to numerous male doctors, who all said it would go away in months, and when it didn't after a bout of traction in yr 10 of high school (yep nursing homes are not the best place for a 15 y.o. to be no matter how close to your family home) surgery was deemed the only options - not one of mine, so I let it be and deal with the pain as best as I could. I also managed to get in the top of some of my classes after spending time in traction - I could say daytime TV drove me to study. I was also excluded from sport on Drs orders, with another friend who had a back problem - the PE teachers just

thought we wanted to get out of it (dang shame at the time -NOT), but what it did do was cause bad muscle wastage, as I was prohibited from everything. This is now not the recommended treatment for OA (funny that).

I finally found out it was OA in 2001, but kept it very quiet even amongst my friends for fear of how they'd react to knowing an "invalid", which was how I took the shattering news I have the hip bones of a senior citizen. I since have not only kept these important people as friends, but they love to take me places when I need it, to law-abidingly use my disability parking permit because of the looks on people places when you park in handicapped spaces - remember that only old people need them apparently, and unless you look like you're 70 in the shade you're too young for anything requiring a disability permit. I have a great lady doctor who took my pain as serious when I decided to finally find out what was wrong with me, and also have a wonderful lady specialist who also refers to me as her 'wondergirl' - apparently because I'm more serious than half her elderly patients, but refuse to sit in a bed and let my disease get the better of me so I get out and about while knowing my limits (or paying for it the next day when I've done a bit too much). She wants a "show and tell" clone me (no not a mini-me) to take to her patients to show them life isn't over when the disease first sets in, and with proper management and a religiously-tailored movement program you to can have a life. She tells me of the people she speaks to at conferences who are amazed at what I still get up to whilst having effectively no cartilage in my hips to cushion the blows. I did though have to give up my beloved Flamenco as the footwork was sending shards of bone into my remnant hip lining, causing pain and swelling the day after - not good, but pain happens after that funnily enough.

I'm also on natural Joint therapy tablets with glucosamine and chondroitin and boy did I know about it when I had to stop taking them when Pan pacific went bung. I'm also on Omega 3 because hey I don't take enough tablets already when you add it to multi-vitamins and the other drugs. (I am refereed to as the medicine cabinet when on hols.). I also firmly believe in the muscle relaxant properties of wine, and have a glass nightly with dinner; especially in winter when it can be my "anti freeze". I am also an avid Yoga nut to keep what is left of my flexibility and movement, and it's also just very good stress and pain relief and I work within my limits. Yoga is also very positive, as whilst I'm crap in some poses, in some other's I'm the best in the class; so it keeps the belief that we are all good and bad in different areas because we are human, alive and well (this is very positive when you feel like crap). I also got depressed when I found out (yep joined that club with many members), but my current 'shit happens" outlook is actually seen as a very positive outlook by my specialist, because I try to be positive and live life.

### **NADINE, Aged 36, has Rheumatoid Arthritis (RA)**

Current Medications: Enbrel (25mg twice weekly) Celebrex (100mg daily) Prednisone (6mg daily), Salazopyrin (1000mg daily), Tramal (PRN)

---

I was diagnosed in late 1987 aged 19. I was in my first year of nursing so luckily was encouraged to see a rheumatologist fairly quickly after noticing the first symptoms which were a very swollen knee and sudden loss of strength in my wrists. A real worry considering I was in the middle of a prac. at the Women's Hospital. It was still some months before a diagnosis was made by a fairly obnoxious Rheumatologist who eventually told me I would be in a wheel chair by the time I was 30. Luck for me, I am a stubborn so & so and him telling me this made me determined never to let this happen.

I started on high doses of aspirin which lead to numerous problems arising from a drastic weight loss associated with the Arthritis. I have been on every known RA medication over the last 16 years except oral cyclosporine, although I did undergo experimental treatment 6 years ago of Chemotherapy (IV cyclosporine) and a bone marrow transplant which had only a minimal effect. I have also tried almost every alternative therapy available, with varied success. I now have the best relief I have ever had due to starting Enbrel.

Despite the Rheumatologist advice to give up the idea of ever being a nurse, I completed my Diploma of Nursing in 1991, working as a psychiatric nurse and returned to University to convert my diploma to a Degree in 1999. Last year I completed a Certificate 4 in Workplace Training & Assessment (TAFE) which lead me to the BEST JOB EVER at the Arthritis Foundation of NSW as an Educator.

I have done a fair amount of travelling, when Arthur allows, and lived & worked for about a year in the UK. Of course the travel bug will never be sated, it has been put on hold for a while as I have just ventured into the housing market and bought my first unit.

I would not have made it this far if not for the love & support of family and friends and finding a Rheumatologist who I relate to. Further more, Knowledge is Power !! Find out as much as you can about your disease and find the things that make you feel good and do them often.

### **SIMONE, aged 32, has Rheumatoid Arthritis (RA)**

Current Medications: Celebrex and Salazapyrin.

---

I was diagnosed in 1999 (aged 27) with Rheumatoid Arthritis. It has always been with me since that day. Even though it has been fairly well controlled with medication, I have still experienced regular flares.

I was taking 400mg a day of Celebrex but I am trying to come off it as I want to try and fall pregnant. I am now taking 100mg a day but will try and come off all Celebrex before trying for a baby.

I have taken Naprosyn, Prednisone and Plaquenil in the past and I am currently taking Fish Oil, Glucosamine and Vitamin C to help also. Whilst coming off the Celebrex, I have been going to Yoga and have had courses of Bowen Treatment, which I find helpful. I have been quite lucky to date and haven't had the greater flares that many in the group have.

I work full time and part time and have completed an Advanced Diploma at TAFE. I got married to Brad in April 2003 and we are both very happy.

### **STACEY, aged 27, has (Juvenile) Rheumatoid Arthritis (RA)**

Current Medications: D- Penamine (250mg daily) and Prednisone (5mg daily)

---

I was first diagnosed with Juvenile Rheumatoid Arthritis at a mere 18 months old so I have lived with Arthritis for 25 years now. I work casually as a Drug & Alcohol Field Officer. I grew up on the Central Coast, NSW before moving to the Upper Hunter Valley with my partner Pete.

I was pretty fortunate to be treated from an early age by a highly ranked group of Rheumatologists at The Prince Of Wales Children's Hospital, Sydney. The specialists treated me with dissolvable Aspro Clear for the first 7-8 years of my life and from there on I felt a guinea

pig, trialing new medications as they hit the shelves. These included Gold Injections, Voltaran, Methotrexate, Gold Tablets, Plaquenil, Nivaquine Syrup, Fergon, Diclofenac, Prednisone and D-Penamamine - just to name a few.

At the age of 3, I seemed to go into remission for 2 years although throughout primary School, I always missed days at school, as I was sore and feeling pretty down. Back then my main worry was my knees. They were constantly swollen and sore and I was having weekly physio sessions at Gosford Hospital.

From age 16 through to 27, I have been up and down (more ups). I continue to have regular blood tests, eye examinations, bone scans and occasional x-rays. I visit my rheumatologist 2 hours away at Kariong (worth the drive) and he keep's a check on me a few times a year.

I have never been a fan of exercise and always cop a wrap for not doing enough. I wear splints on my hands at night, as they are my main concern now, and I wake in winter feeling a bit slow (but it doesn't take long to warm me up). For me, pushing myself to walk on the bad days is crucial. Going to work when I'm sore is crucial. I refuse to let this disease rule my life.

### **STEPHANIE, aged 31, has (Juvenile) Rheumatoid Arthritis (RA)**

Current Medications: No regular medications at this time

---

I was diagnosed with Juvenile Rheumatoid Arthritis, or to be specific Stills Disease, when I was 18 months old. However I had been having symptoms of the disease for 4 months previous to that.

Leading up to my diagnosis my mother tells me I had symptoms such as swelling in my left ankle which promptly spread to my knees and further up my body. I had high temperatures and chronic pain and stiffness. Later on when I was about 3 years old I had a major flare up and suffered kidney and liver failure and was admitted to the intensive care unit. The doctors I remember seeing throughout this epic stage of my life were Dr Ziegler and Dr Champion at the Prince of Wales Hospital. I probably saw others but they were the main ones that I remember. I spent so many years in hospital as a child that it all blurs together.

Since being diagnosed with Arthur I have been on so many medications that I can't remember them all...and I was too young to know anyway. Some that I do remember are Brufen tablets, gold injections, prednisone, cortisone, aspirin, hydroxichloriquin.

I wore leg and wrist splints at night when I was about 10 years old. I also had traction on the end of my leg splints which I detested greatly. This was supposedly to help straighten my knees as they were fixed in a very flexed position. I've also had the mandatory physio and hydrotherapy sessions.

I had my left hip replacement in 2001 and my right hip replacement in 2003. I am due to have both knees replaced in the future but I'm holding out as long as I can.

I am not currently taking any medication and have not needed any since my hip replacements. For this I am eternally grateful. Previous to the operations I was taking daily dosages of Celebrex (500mg I think). Tried Vioxx but it didn't seem to work as well. Without the Celebrex I could not walk.

Over the last couple of years I have had a few Cortisone injections in my knees to help with the pain and mobility, but have not had any for some months now as I choose to manage the pain

without drugs. I do this by generally not overdoing the physical stuff and listening to my body when it tells me to sit down and rest. I also try to keep my muscles strong in order to support the joints. I do this by going to the gym 3 times a week (when I am feeling up to it) and swimming.

My teenage years were pretty much pain free and my early twenties were good too. I suffered chronic lower back and hip pain in my late twenties until I had the hip replacements. Now I'm into my 30's and life is starting all over again. I have not married or had children yet, but I have been to University and become a primary school teacher. I have been teaching since 2000 and I find it very rewarding. The thing I am most grateful for is my ability to be independent and live on my own in a place that I love here in the Blue Mountains.

### **SUSAN, aged 38, has Unclassified Spondyloarthritis**

Current Medications: Using alternative and natural therapies (including vitamins, minerals and supplements).

---

I was diagnosed a year ago with unclassified Spondyloarthritis, yet unlike most people with arthritis from this family (which includes Reactive Arthritis, Psoriatic Arthritis & Ankylosing Spondyloarthritis), I do not have the HLA-B27 gene. However my brother who has the B27 gene has AS.

Initially I was taking Prednisone & over 4 months was decreasing the dosage. Whilst my rheumatologist was keen for me to just take Methotrexate, I read the side effects and became VERY motivated to avoid if possible as I'm still thinking of having another child. In an attempt to find an alternative treatment, I went into research overload which was challenging as spondyloarthritis is not so common.

I began taking antioxidants, multiminerals, calcium, glucosamine & flaxseed oil. I visited an alternative doctor who explained that my immune system was out of balance, so for about 6 months I also took astragalus, leucostat, acidophilus and evening primrose oil.

My body responded well & I have been off the Prednisone for 7 months. I have an occasional day where I feel achy & I pop some EPO which seems to settle it. I continue to take antioxidants & minerals to ensure my immune system is supported & as these products are so great I also distribute them. (Happy to talk with anyone if they want to know more about the products).

I am married to Bob, and have a 3 year old daughter. I have studied Food Technology and currently work part time in a home based business.

### **SYLVIA, aged 34, has (Juvenile) Rheumatoid Arthritis (RA)**

Current Medications: Oral Methotrexate (25mg weekly on Wednesdays), Arava (10mg daily – 20mg daily didn't agree with me), Vioxx (25mg daily) and Prednisone (10mg daily)

---

I am 34 and was diagnosed with Rheumatoid Arthritis (RA) at 16. I played competitive tennis when I was 12 and about a year later I started to have problems with my ankles. Gradually other joints were also affected (and I realised that I wouldn't be the next Stefi Graf).

When I was 17, I was hospitalised to get the RA under control. Numerous medications were introduced and I was able to return to school and sit my HSC (final year exams). Unfortunately, I didn't do well at all at school but that is no longer an issue for me.

At that time, I was on a combination of Plaquenil, Voltaren and Methotrexate. I did very well for a number of years until I had some abnormalities with my left eye and a stomach ulcer. I had to stop the Plaquenil and Voltaren as a result and have been on a bit of a roller coaster ride since. At the moment, my rheumatologist and I are working towards one of the newer drugs.

I refuse to give up and stay at home as I'm too busy. I work full time, I enjoy reading, gardening, sleeping, eating (tasting anyway) and I love socialising (not that you'd ever guess). I am also "mum" to 5 "babies" (my 2 dogs and 3 cats). The motto "Move it or Lose it" is so true and the words "I can't" or "I shouldn't" don't even enter my vocabulary.

I do meditation / relaxation, aqua aerobics, walking and am going to give yoga a try. At the end of the day, its important to decide what quality of life you want. It's important to still focus on positive things. There are still bad days and obstacles but you get to choose which attitude you have. And remember, its okay to ask for help.