MEET THE
'Little Women'

Profile in courage
An ongoing series of interviews with people who make a difference.
by Meryl Dorey

When Rosemary Mathis’ daughter, Lauren, was seriously injured by her Gardasil vaccinations, she didn’t just sit back, wring her hands and ask “Why me?”. Instead, she joined forces with other parents across the globe to initiate a grass-roots movement to support and inform others who have Gardasil and Cervarix affected children. Their research and information distribution has been so effective, they have been asked to present their data to the US Food and Drug Administration (FDA). Together, they are called the ‘Little Women’ but the effect they are having on the entire pro-health choice movement is anything but ‘Little’.
You became involved in the vaccination information issue because your daughter, Lauren, reacted to her Gardasil vaccines which she started to receive when she was 12 years old. Can you tell me a little bit about what happened to her after her vaccinations?

After her first two doses of Gardasil, Lauren suffered with stomach pains, headaches, and nausea. Her doctor said she had a virus which was not related to the vaccine.

She was treated by both Wake Forest and Duke University Hospitals – both very prestigious teaching hospitals in my area. Lauren gained 40 pounds (almost 20 kilos) because when her stomach was bothering her, she ate to relieve the pain. Doctors at Wake Forest did an upper GI and said that she had sores in her gut. She also failed a Hida Scan for her gall bladder on which she scored a 7 which is non-functioning. They couldn’t figure out why a 12-year-old girl would have these symptoms. They settled on it being her gall bladder. They said it had stopped functioning. She also had a constant low-grade fever so the doctors suspected it was an infection and put her on a heavy course of antibiotics.

My now 14 year old daughter received her third and final dose of Gardasil on August 18, 2008 just days before her 13th birthday. By the beginning of September that year (less than 2 weeks after getting the shot), she was completely bedridden.

I soon begin to spend my days going to doctors who ran round after round of tests. In total, she was treated at four different hospitals.

Because of her vaccine injury, she was placed on a modified school schedule with the state of North Carolina. My daughter was in the academically gifted program in her school system. Because she was such a good student, she had no trouble getting placed on a modified schedule. Her problem was trying to keep up her studies while being bedridden.

My 13 year old missed almost her entire eighth grade year of school! Some of her symptoms were enlarged liver, gall bladder attacks, severe nausea, chest pain, severe abdominal pain, severe headaches, brain freezes, stomach ulcer, and sensitivity to light.

She became severely depressed because she could not attend school or be with her friends like a normal child. Because of Gardasil, she was ‘One Less’ in all aspects of her life.

She went from being an academically gifted student to one who struggled to complete her eighth grade year of school. Her life became an endless round of hospital and doctor visits with little resolution to the severe pain that she was experiencing.

She was even sent for surgery on her gall bladder at Wake Forest Baptist Medical Centre in Winston Salem, NC where a skilled surgeon recognised that the symptoms were more than gall bladder dysfunction and thankfully did not operate.

We have spent the past year researching this horrible vaccine and the side effects and treating her with vitamins and other medicines.

My daughter was treated by both Wake Forest’s Brenner’s Children’s Hospital and by Duke University’s Children’s Hospital where the bills ran into the tens of thousands of dollars. Thankfully, I have a good insurance policy that has helped cover the costs associated with the effects of Gardasil.

Lauren still attends school on a modified plan. She goes to school when she can and, provided she keeps up with her schoolwork, she can miss as many days as she needs to.

Last year, she missed about 85 days and of the days she has been able to attend, most of them were only ½ days or maybe a couple of hours a day. This year, she is doing better and has only missed about 20 days. I’d say she is approximately 80% well thanks to the diet, vitamin and other therapies she is now on.

We are lucky because she has recovered a lot better than many others I know.

Before her reactions, were you someone who just went along and got vaccines without questioning what was in them or how effective or necessary they were?

Yes. Before Gardasil, I had complete trust in my doctor and the medical system and believed that I should allow my children to receive whatever vaccination my doctor recommended. I truly thought I was doing the best thing for my daughter and that my doctor had her best interest in mind.

How has your attitude changed since then?

I can assure you, I will never make that mistake again! I have a teenage son. My son will never receive the HPV vaccine. The benefit of the vaccine in NO WAY outweighs the risk.

I trusted my doctor and did everything he said I should. Before Lauren’s reaction, I wasn’t even aware that some people could have problems with vaccines.

I believe my doctor didn’t have enough information before offering this vaccine. I do not feel he was aware of the true side effects though I don’t blame him – he used the information provided to him by Merck which doesn’t show all the side effects that the Gardasil victims are having.

Did you start the Let’s Talk About Gardasil email discussion group?

No. Let’s Talk About Gardasil was started by Anita Tindell of Tennessee, a neighbouring state to North Carolina where I live. She started it when her daughter was injured and she didn’t know where to turn. Both Marian Greene and I quickly found the Let’s Talk About Gardasil Yahoo chat group after our daughters became injured after receiving Gardasil. We soon realised that we were not alone in our journey. Nightly,
mothers would appear in the group, distraught and frantic about their daughters' injuries, trying to discover what to do to help their children. We met hundreds of mothers via this venue and more continue to come all the time.

**How has this forum grown and where have you gone to from the beginnings of Let's Talk About Gardasil?**

Even though Let's Talk About Gardasil was a wonderful forum for mothers of injured children to turn to when their child became ill, Marian and I recognised that we needed something more. Marian and I decided it was time to do more than just have the Let's Talk About Gardasil Group. We wanted a way for victims to quickly become organised once they were injured so they had a better chance of recovery and a good support system. That is when we stated another Yahoo chat group called Truth About Gardasil (http://health.groups.yahoo.com/group/Truth_About_Gardasil/) which we both administer.

We also have a forum on our website, TruthAboutGardasil.org, along with Facebook (http://tinyurl.com/2fnq2c2), and YouTube (http://tinyurl.com/2g2w7yc). Each night, mothers gather all across the Internet to discuss their daughter's Gardasil injuries and compare treatments. It is amazing that there are so many injured girls, but horrible that they have to be there.

**When did you launch the TruthAboutGardasil.org website? Why did you decide to set up a website about this issue and what has the response been from the community since it started?**

Both Marian's and my daughter became injured in 2008 from the exact same lot number of Gardasil – lot number 0067X. (Editor's note: In the US, the national reporting database, VAERS, keeps track of the lot and batch numbers which help to identify who is reacting to what vaccine. This way, so called 'hot' or especially reactive lots of vaccinations can be identified and hopefully withdrawn. In Australia, there is not even a field on the reaction report form for this information to be noted!)

It was through our efforts that we found and identified several 'hot lots' of Gardasil vaccine.

In 2008, the FDA cited Merck, the manufacturer of Gardasil, for not having their Pennsylvania plant up to code. We wanted to find out if the lots we had identified as being more reactive came from this plant.

When we asked however, Merck told us we would need to get a lawyer to get that information! Then, the search engine for VAERS was changed, making it harder for us to even identify which lots were causing the most reactions.

Even though we both live in North Carolina, Marion and I did not know each other at the time of our daughter’s injuries. As we continued to research our daughter’s Gardasil injuries and try to find some sort of help for them, we became friends on Let's Talk About Gardasil.

We soon realised that a chat forum for discussions was not enough. The mother’s needed organisation. They needed a place to call their own.

In 2009, we decided to build the website, TruthAboutGardasil.org to help the current and future victims of Gardasil. This site:

- is built by parents of victims to aid others in finding information and medical resources;
- is a place to unite the victims of both Gardasil and Cervarix (the other HPV vaccine, produced and marketed by GlaxoSmithKline) vaccines;
- represents families from the United States, New Zealand, Australia, the United Kingdom, France, Germany, Spain, Russia, Mexico, Japan, the Netherlands, Turkey, Canada, Belgium, and India;
- houses injury and memorial documents of Gardasil victims for future reference by medical professionals, parents, and victims;
- gives the victims of Gardasil and Cervarix a voice and is a forum for representation of these victims to their elected officials;
- is a resource which includes support groups made up of victims and/or their parents, sorted by state and/or country, to allow contact and support and to aid others through the unknown situations they may find themselves in related to vaccine injury;
- provides a place for victims to voice their concerns;
- maintains a centralised repository for information related to both Gardasil and Cervarix;
- includes the most up-to-date news, information and guidance including how to report injury information; and
- provides support via The Guardian Angels – a group of volunteers that are there to help – whether it be to answer questions or just provide some emotional support.

One more note: see the graph below. Look at the international presence on our site. There are many countries using our site as their own and converting it over into their own language. It is amazing.

We get emails in foreign languages and use Google Translator to convert it over to English so we can communicate with those in other countries.

![The Truth About Gardasil Country Share](image-url)
Do you get much flack from the medical community regarding your activism?

To date, we have not had any issues.

When we built the site late last year, we had no idea how much of an impact it would have or how large the side effect problems from the vaccine Gardasil had become.

At first, the doctors didn’t seem to think Gardasil caused the issue. My daughter became injured in 2008 when the vaccine had only been on the market a couple of years. But I am an accounting manager for a Fortune 50 company in the United States. I keep really good records, so when my daughter became ill, I charted her injury, her symptoms, her progress, etc. and presented it to the university hospitals where she was being treated. I am very lucky in the fact that I live near some of the finest hospitals in the United States.

It was very apparent that she was suffering from a vaccine injury. The vaccine was new and the doctors didn’t understand the side effects yet – partially due to the fact that full disclosure details have not been included in the Gardasil pamphlet that is used for reference.

This information has been revised since my daughter received the vaccine, but at the time my daughter received Gardasil, the side effects were communicated to me as only redness and swelling at the injection site.

Based on the records I kept, it was apparent what caused Lauren’s injury. I always tell the doctors that I was an eyewitness to the tragedy that occurred and I have NO DOUBT what caused my daughter’s injury. I watched in horror as the vaccine disabled a perfectly healthy 13 year old who had no previously known illnesses.

I have had a good relationship with my daughter’s doctors at Wake Forest and at Duke University and she continues to see the same paediatrician that recommended the vaccine. I do not hold him responsible, but believe the vaccine maker, Merck, obviously did not do the amount of research and development needed prior to marketing this vaccine.

Other then that, I have to say that I haven’t gotten any flack. In North Carolina, both Duke and Wake Forest encouraged me to pursue my research.

We have had some issues with people trying to hack my email account and Marian’s account as well. But other then that, there haven’t been any problems.

Do you work with any of the Australian activists on this issue such as Dr Renate Klein?

Yes, Dr. Klein has worked with our team and aided us with research and questions. We have also participated with Dr Klein in setting up a blogsite which tracks reactions to Gardasil in Australia. The site is called Gardasil: Women Hurt by Medicine. (http://womenhurtbymedicine.wordpress.com/)

Just recently, the US Food and Drug Administration (FDA) took the unprecedented step of asking you and several other women you have worked with to present your research into the dangers of Gardasil. You called yourselves the ‘Little Women’, but your effect has been anything but little! How did the FDA meeting come about and how did you start working with the other ‘Little Women’?

Last fall, I was asked by Freda Birrell (birrell_df@btopenworld.com) of Scotland to help her gather the stories of the young girls who had been injured and/or died due to Gardasil reactions. She was preparing a letter to Margaret Hamburg, M.D., Commissioner of the FDA, on behalf of Karen Maynor who lost her daughter, Megan, after Gardasil.

Being an accountant, I had naturally been researching the Vaccine Adverse Events Reporting System (VAERS) database for some time, so I was very familiar with the data. I worked with the other ‘Little Women’ and aided them by writing the part of the letter that referenced the VAERS reports.

That letter from the Summer of 2009 resulted in three meetings with the FDA. For the last meeting that was held on March 12, Janny Stokvis from Holland aided by providing details from the VAERS data I used to create the graphs we ultimately presented to the FDA.

I met all of these ladies on the Gardasil group board in early 2009 as I was investigating my child’s injury and trying to aid the other mothers. We quickly joined forces and created the ‘Little Women’ team who did the research and we presented our data to the FDA on March 12, 2010. (http://truthaboutgardasil.org/additional-webinar-documents/)

The FDA only allowed us one hour to present 243 pages of information so we really had to present quickly! We posted all of the data and references on our website and afterwards, they contacted us to follow up and ask for further information and all of the available backup. They said they would have their researchers look it all over and get back to us in a month. It is now over a month since our presentation but we still have not received any response from them regarding our presentation.

Regardless of their lack of response, the FDA now knows (if they didn’t before) that they have a real problem on their hands.
If you look at the graphs done for VAERS (above) – Gardasil has the highest number of reactions for any vaccine so if the FDA doesn’t accept that there is something wrong, that is a real concern.

Have there been any successful legal actions against either the government or the drug company because of injuries or deaths caused by the Gardasil vaccine?

There have been lots of lawsuits, but it’s too soon to have had any results yet. I would like to see a class action filed and several people have tried to get one together but so far, for one reason or another, there hasn’t been a class action for Gardasil.

What do you consider the biggest lesson you’ve learned as a result of the journey you and Lauren have travelled since her reactions to Gardasil?

This whole situation has been a shock to me. If this hadn’t happened to Lauren, I never would have chosen to investigate before I vaccinated. I trusted my doctor and never thought to question anything he told me.

Now, I would do things very differently for my grandchildren.

I would also never give my son the Gardasil vaccine.

In the US, Gardasil was approved for boys on October 16th, 2009 and started to be used officially on April 13th 2010.

I guess the fact that Gardasil has been marketed as a cervical cancer vaccine and men and boys don’t have a cervix has got to make people question what it is we’re really doing.

We have had men contact us who have reacted to Gardasil. They have no idea what to do.

As a result of my family’s experience with Gardasil and due to the others who I have been in contact with regarding this issue, my attitude towards medicine and personal responsibility are now quite different.

If I had it all to do over again, I would have certainly been better informed before I made a decision to listen to my doctor and have my daughter vaccinated with Gardasil.

References
2. Lets_Talk_about_Gardasil@yahoogroups.com

Need to report a vaccine reaction?
It’s more common than you think.

Call the AVN’s toll free number or fill out a reaction report found on the website.

1800 007 468

www.avn.org.au