

# MRSA Resources

Dedicated to MRSA Education and Community Awareness

## Special points of interest:

- Don't miss Tony Field's story taken from his speech in the US on August 25, 2005!
- See page 11 for a chart about preventing skin infections!
- Mark Thursday Nights on your calendars, as we meet in the chat room for the MRSA Chat!

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MRSA Resources

Volume 1, Issue 1

## Welcome to the Premiere Issue!

It is so difficult to know where to start. I am determined to get our first newsletter out by October 1st. I am sure that there will be many changes along the way, but the one thing that will not change is the goal of our group to offer support to one another and to raise awareness in an effort to prevent MRSA and other Hospital Acquired Infections.

The summer sped by and, little by little, I am becoming less nervous about my children getting re-infected. I have been blessed in many ways, most importantly to me, in my children's return to good health. My life is very different today than it was at this time last year. Last year, Emily was still sick and Jeanne was still MRSA infection free. It was a very difficult time for our family. Little did I know, it was going to get worse before it got better.

There are so many things I'd like to tell you all about and there are so many things I'd like to hear from all of you. Our group is a work in progress. We have come a long way and we have a long way to go.

Tony & Barbara Field spent two weeks in the USA and Canada to help us raise awareness about MRSA, just as they've done in the UK. In the UK, MRSA is something that nearly everyone has heard of. It has become a political issue because people don't want to be afraid to go to the hospital. Through tremendous amounts of effort by the MRSA Support Group UK, people know about how these infections are spread in Great Britain. This knowl-

edge empowers the general public to make educated decisions about their medical care.

In our country, we need to be empowered with knowledge, too. This is the only way we can protect ourselves and our loved ones from this highly preventable infection. People need to know that not washing your hands today can make you vulnerable to far more serious things than an ordinary head cold.

Our medical professionals and politicians need to be made more aware of what is happening around us as well. They need to know that we won't accept antibiotic resistant infections as an inevitable outcome. Most cases of MRSA are preventable. And the same steps one takes to protect oneself from MRSA infection should help reduce any number of contagious illnesses as well. We need to go back to the basics when it comes to hygiene and disinfection.

We need help from our doctors, hospitals, school administrators and athletic coaches to make our prevention campaign a success. If there is someone you would like to receive the information packages for professionals compiled by our group, please mail or e-mail their address to us. We have gotten quite a bit of positive feedback, especially from physicians, about the information we're sending out. As a last note, I've heard MRSA referred to as a lonely illness. I hope and pray that our group and this newsletter can help to put a dent in that loneliness.

God bless you all!

Denise

Disclaimer: This group is made up of normal people. While some of us may be in the medical profession, we advise you to see your physician if you think you may have any illness or infection. If you choose to use any information on these pages, DO SO AT YOUR OWN RISK. No clinical decisions should be made solely by the information contained herein. We try to provide quality information, but cannot make claims, promises, or guarantees about the accuracy, completeness, or adequacy of any information contained in or linked to this website and its associated sites.



**Maureen Daly is a volunteer with RID and has been working closely with our groups as well. Find RID online at <http://www.hospitalinfectionrates.com/>.**

*“We were shocked by how accepting the administrators of the Hospital for Joint Diseases were of this horrible tragedy. It was quite simply no big deal to them.”*

## Bio: Maureen Daly

In January 2004 my mother, Johanna Daly, entered the Hospital for Joint Diseases in New York a healthy 63 year old woman. She had only a broken shoulder. Mom contracted infections in the hospital among the infections were MRSA. My poor mother suffered horribly for four months due to these infections. She became a unable to move anything but her head, she was incontinent, on a ventilator and a feeding tube. Perhaps the most difficult thing was that she had horrible difficulty communicating. She sounded as though she had suffered a stroke when she spoke. But she had not had a stroke all of her suffering was caused by infections. On May 23, 2004 my mother died as a direct result of the hospital acquired infections. I knew that nothing would bring her back. I was angry and heart bro-

ken. An administrator at the Hospital for Joint Diseases told me that these infections and deaths happen everyday in every hospital all over America. I was told that I would just have to accept that these things happen. I was told that these infections are "the cost of doing the business of medicine." My anger now became outrage. I thought it was bad enough that my mother had died from complications from a broken shoulder. My family and I had thought it reasonable to believe that one should not die from a broken shoulder. We were shocked by how accepting the administrators of the Hospital for Joint Diseases were of this horrible tragedy. It was quite simply no big deal to them.

My anger lead me to write many letters of complaint and inquiry. Most went unanswered. In March 2005, I heard of

a group named RID or the Committee to Reduce Infection Deaths. I became the first volunteer. We work everyday to reduce infection deaths nationwide. We are confident that we will be successful. We are determined to prevent others from suffering my family's tragedy. We were delighted when Governor Pataki signed the "Hospital Infection Reporting Bill" into law on July 21, 2005.

My work with RID introduced me to Denise. I am very pleased to join forces with her and her organization. I am happy to support her and Hands of Hope/MRSA Support in any way I can.

I applaud Denise and the MRSA SUPPORT group for their hard work and efforts.

**Special thanks to Donna Vaughn and Long Island, NY's 97.5 WALK radio for helping us promote MRSA Awareness and the Hands of Hope Documentary !**

## Writing Campaign for MRSA Awareness

We have been inspired by Michelle Wells' article she submitted to her local newspaper last month, and would like to encourage you all to do the same. Michelle's article was passionate (as she is about MRSA), stern, and provided solutions to the problem, rather than just a complaint about the way that MRSA is consistently swept under the rug.

Many of you have equally passionate feelings about MRSA and what it has done to your lives. We would like to encourage our readers to submit an article or a letter to the editor of your local newspaper. This is a small thing, that we can all do, no matter where we are, or what our background might be, that taken together can be a giant step in letting our communities know of

the dangers of MRSA and how to prevent MRSA from touching their lives as it has all of ours.

If you would like, send your article/letter to [news@mrsaresources.com](mailto:news@mrsaresources.com), to reprint here and inspire others!



**Consider writing your local newspaper!**

## We Will Walk Hand in Hand by James Rauff

We will walk hand and hand  
 And I will offer you to do the same  
 We will use our voice for song  
 And try to strengthen our chorus

We won't sing about being the smallest common denominator  
 Or the calculated risks of procedure  
 We won't sing about tragedy or despair  
 Or the growing number rapid cells

We will take our hands and cleanse them  
 And I will offer you to do the same  
 We will use our voice to clean these walls  
 And try to cleanse the air

So for now I'll take these strides in small steps  
 Sing these songs in short breaths  
 Take this road that is unkempt  
 And hope that you will join along



*James Rauff is the son of Rich and Denise Rauff, and was part of the film crew for The Hands of Hope Group documentary .*

*“Using a Wiki is not hard, it is just very different from anything you have used on the WWW before. Please, just give it a try!”*

## Newsletter Submissions:

We are dedicated to bringing you quality stories and information in our monthly newsletter. We invite you to submit your stories and articles on anything relating to MRSA and Superbugs for consideration for publication in the newsletter and / or on the web site . Please have your submissions turned in to us at [news@mrsaresources.com](mailto:news@mrsaresources.com) no later than the 15th of the month for consideration in next months issue.

We are always looking for new ways to help make our communities aware of MRSA. If you have ideas, or have done something yourself, please let us know so that we can let others be inspired by you!

Also, we would love to post your MRSA related events on the newsletter calendar, as well as the calendar on the website. Again, have those in to us by the 15th of the month prior.



## The Hands of Hope Group Documentary

*“It really keeps amazing me how so many people made such an effort in order to raise awareness and just to be part of something special.”*

Well I am not quite sure how to start this off. The past few weeks have just been pretty amazing in many ways from the things we set out to accomplish, to the people we have meet along the way and the strong bonds that we have made. It really keeps amazing me how so many people made such an effort in order to raise awareness and just to be part of something special.

First off I would like to thank Denise for all the sacrifice and effort she put into organizing the documentary and the other efforts to strengthen the voice of MRSA victims. I would also like to give a heartfelt thanks to everyone we interviewed from England to Texas and all of our stops in between. With out the support from you guys this would not have been possible at all. Also I would

like to thank Jeff for being a great friend and such a good co pilot while I was driving.

It was such a weird experience at first, us being so far away from home driving for hours until state lines melted together and became meaningless. The asphalt looks the same in Georgia as it does in as it does Florida. The difference is oranges and peaches. The trees were broken in Louisiana as they were in Mississippi. And then there was Jeff and I somewhere in a hotel room. Sitting down try to think of interview questions for people who never had really met, people who we knew only from telephone calls or just through stories of near survival. And we had to ask questions like, “ Were there any particularly bleak moments that you remember?” Trying to sugar coat to obvi-

ous question, did you ever think this said person would die? As hard as it was to ask, I'm sure it was harder to answer. Yet everyone answered with openness and optimism. And I want to seriously thank everyone who we talked to and helped us out along the way for allowing us to ask you these things and for sharing your story for us and for others to hear.

I think the effort that was put into this from all people and the connections that we made from many states all the way to Canada, speaks volumes about the future we have ahead of us and how many people are willing to join us in order to raise awareness.

James Rauff

The Hands of Hope Documentary is due to be finished this Fall.

### Schedule of Events

- MRSA Chat—Every Thursday at 10pm Eastern time (US) . Register at <http://www.discuss.superbugwiki.com/>, and log in to the FlashChat from the front page of the web site.
- International MRSA Chat—Meet in the chat room on the last Saturday of every month at 5pm Eastern time for the International MRSA Chat!
- If you would like a reminder for our chats, send a blank email to: [MRSAResourcesChat@getresponse.com](mailto:MRSAResourcesChat@getresponse.com)

# October 2005

Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
2	3	4	5	6 MRSA Chat 10pm Eastern (US)	7	8
9	10	11	12	13 MRSA Chat 10pm Eastern (US)	14	15
16	17	18	19	20 MRSA Chat 10pm Eastern (US)	21	22
23	24	25	26	27 MRSA Chat 10pm Eastern (US)	28	29Internat'l Chat 5pm Eastern US
30	31					

## Focus on Awareness: A Letter to the Newspaper by Michelle Wells

I'm not writing this letter to the editor to cause panic or to say to everyone run to your doctors immediately but only for awareness. The people of this town and every town around need to know about a disease that is spreading through our communities. Awareness is the only way to prevent the spreading.

The disease I am speaking of is called MRSA. In medical terms it is METHICILLIN RESISTANT STAPH AUREUS. Or also know as the "super bug". In my opinion it should be called the "life ruining devil." This disease is serious and can even be deadly. Too many doctors sugar coat what it is. We have only found one doctor that has been honest with us about this and the rest of the information I researched online. I have also found a wonderful support group to help us with learning what my family and I will have to live with the rest of our lives. The doctors say that it can be cured and you can be rid of this but that's such a HUGE LIE. I have yet to hear one story where a person has been "cured" for life.

MRSA is a staph infection that lives in the nasal passage. If you have MRSA the first signs are fatigue, flu like symptoms, then you get a sore that can be anywhere on your body. The sore will get larger each day and it will look like a boil. A normal boil will be sore but these are down right painful. There will be redness around it that will be warm to the touch. Drainage will eventually happen when it gets large enough. If this is not treated it can be

deadly. Later I will give the support site and there you can read survival and death stories. Many of us with this have numerous hospital stays to get it under control. We all have a staph on us but when you get this it enters into your blood stream then you are stuck with it.

The majority of you have never heard a word of this until now. That's because the doctors aren't treating this as serious as need be. Now some of you may be saying, well if the doctors say that then why worry. Let me tell you why. We live with this and know the pain and suffering of it. If it wasn't serious then why do we get so sick and why do we have to be hospitalized to get under control? And why are we told that SKIN TO SKIN contact can spread this? So to all the doctors who sugar coat this GET A GRIP ON REALITY! Tell the truth and let the people know.

Now I am going to let you all know about prevention. Prevention is the main thing we have to worry about at this point. All doctors are worried about how to take care of this but none of them tell you how to prevent this. Its as simple as washing your hands. I don't mean the normal washing after going to the bathroom, but washing after touching things that others touch or after sneezing or coughing. If one has this and sneezes or something then shakes another's hand, guess what, you just spread it. PREVENTION is the main key and there's much more to learn about that. I only have so much

room to write though.

Here is our story.

Over a year ago now my husband was sent to Iraq to do his duty for our country. While there he broke out with these boil like sores. Since he was in war they gave him an antibiotic and sent him on his way. This may be a good time to let you know that the R in MRSA means resistant. Resistant to ANTIBIOTICS. So he went about his job there with not a second thought. When he came home he was broke out again with 2 boils and man did they look nasty. I sent him to the Williamsport hospital. They gave him more ANTIBIOTICS and also too a culture of the puss that was seeping out and said they would call if anything showed up. 2 months later he once again broke out and I sent him back to the ER. The doctor looked up my husbands records and noticed that it said MRSA positive. And no one called to let us know these results. Knowing that, the doctor put him on a medication that would work, but the meds only work to clear up the infected sore. All he told us was to keep it clean and finish all his meds. NOTHING ELSE! Since then my husband has gone back to the ER MANY times to get his sores drained and then packed with gauze.

Now here we are over a year later and let me tell you what has happened since then. A month ago my daughter broke out with 2 sores on her belly. Knowing what my husbands looked like we took her straight to the hospital. The

doctor that saw her that night said it was spider bites. She took no culture at all even though we told her that my husband has MRSA. Within 3 days her sores got so much worse so we took her back out. The doctor we saw then was a GOD send. He took one look and knew right away that it was MRSA. He put her on the right meds and cultured it to be sure. 3 days later they called saying she was positive.

A week after that my mother in law broke out with a sore, and a week after her I myself broke out. We both tested positive. Worrying about our other 2 children we got them tested as well and they are also positive. We continue to break out at least once a month each. Right now my husband has to have surgery on his recent one to clean it out.

I know that if only the doctors would have informed us about MRSA and how it is spread over a year ago when my husband was diagnosed, our children, myself and his mother would be MRSA free.

I wanted to get answers to all my questions about this. Even though doctor Bruce Body at the ER was honest with us, his knowledge on this was limited. He was the ONLY one who gave us any info at all. So I went to our doctor that the kids see out at the Divine



“It’s our right as human beings to know what is out there”

## A Letter to the Newspaper by Michelle Wells (continued from page 5)

clinic to ask my questions. When I asked her about telling the schools my kids attend I was in shock when she told me not to because I would cause a panic. I did anyways. What an awful doctor to say something like that. Not only would we have been putting all your kids in harm way of getting it but the teachers as well. Don't worry parents, we now home school our children for your child's safety and mine. If my child gets your child's cold or flu it could mean a hospital stay for mine because MRSA weakens the immune system.

I am outraged that the government hasn't said a word about this. Especially when I was told from EVERY doctor I spoke to that MRSA is spreading like wild fire through Williamsport and surrounding areas. People need to know what they are in harm of and how to PREVENT it. This has even affected my husbands jobs.

He has lost 2 in the past year due to this. Mainly because he gets so sick and when he breaks out he is the most contagious and not to mention in pain.

I know that there are many of you out there that have MRSA and if you are interested in starting a support group here in Williamsport I would be happy to get emails from you. you can email me at [allthawaynavy5@aol.com](mailto:allthawaynavy5@aol.com). For those of you who are interested in learning more and reading others stories you may also visit the support site online at <http://www.mrsasupport.co.uk>. We have learned most of what we know from there and have gotten wonderful support from others with this. Believe me there is A LOT more to learn.

I say to the government that if you wont let the people know about this then those of us who have MRSA WILL make it known to all. Its our right as hu-

man beings to know what is out there! It is you who we depend on to let us know, but you're not doing your job! You are letting us suffer and don't look back. Who do you think you are! The secrets out and there's nothing you will be able to do to stop it. I challenge you to try.

Michelle Wells is a member of MRSA Resources from Williamsport, PA.

## Donations



If you would like to make a donation to help with the costs of our campaigns, please go to <http://www.handsofhopegroup.com/donate.html>. And thank you for your kindness!

## Focus on Education: The Superbug Wiki

In this area, we will highlight areas of the Wiki, and give you tips on how to use and edit the Wiki yourself.

The Knowledge Base is the area of the Wiki with the “meat” of the information. Starting on that page, you can find alphabetically listed and linked terms. Click on those links, and you can go to a page with more information.

What if you don't see what you are looking for? This is the beauty of the Wiki format. Look at the main Knowledge Base page. At the top you will see a row of tabs. Look for the edit tab and click on it. On the screen

that follows, you will see all the information on the Knowledge Base page in a format that you can easily edit. Don't worry about making It pretty, you can learn how to do that later, or never. Just get the information down on the page that you want to see there, and someone will come behind you and format it correctly, and maybe even offer some information to fill up the page for the link you just created.

Using a Wiki is not hard, it is just different from anything you have used on the WWW before. Please, just give it a try!

Our October Superbug-Wiki focus will be on Pets with

MRSA, and the Superbug FAQ please come give the Wiki the ol' college try!



Join us at the Superbug Wiki for interactive education and more!

## Tony Field: My Story For America (from his speech, Aug. 25, 2005)

Good evening, thank you for your welcome, and thank you to Denise Rauff for inviting Barbara and myself to your great country. We are here to listen and learn what is happening here and to tell you what is happening in the UK.

I'm Tony Field and I suffered MRSA FOR THREE YEARS. This is my story.

It was 7 o'clock on a Friday evening and my pathetic waving from a prone position, with a handkerchief tied to the handle of a grass trimmer trying to attract the attention of my wife had to defer to the major soap opera in England-Coronation St. When the ambulance was called they asked her if I was still breathing and told her to go and check! So we had the bizarre shout along the garden for all the neighbours to hear--"They want to know if you are still breathing".

The X-Ray confirmed rt. femur broken. I was held in the local A&E Hospital for nearly three weeks until a bed was available at the Royal Orthopaedic. During the stay in the A&E hospital I was confined to the bed on traction and with a Thomas splint, at the top end of which was an enormous metal hoop with a leather covering which meant that I couldn't wear pyjama trousers. By the second week I had bed-sores, and was constipated.

The most notable points I remember from this stay was the incredible work rate of most of the nurses, and their lack of time

to stop and talk to the patients, and the absolute lack of hygiene discipline from and to the patients.

An example of this was Michael who spent much of the time deliriously talking about the women he had been with, playing with his private parts and detaching his catheter in full view of everyone. I still wince when I think about it! Because the nurses were so busy they would just come and admonish him and replace the catheter without cleaning it. Then I was moved to another bay, and placed next to a man who I can only describe as the bravest I have ever met.

Stan was an ardent soccer fan. He told me that regularly he would visit the training ground of his favourite club Aston Villa and watch the players training sessions. He had retired just three months previously. Stan was a keen motorcyclist and on his way to watch a training session one day he was hit by a truck emerging from a side road. When I met him in that ward he was minus both feet, and in the week I was privileged to have met him, never once did he say - "Why me"?

During the early hours of the morning after Sister Shirley's' laxative was administered, the bedpan was called for. I found it somewhat difficult to clean myself while hanging onto the over bed handle, and the nurse refused to help. "We don't do this now" she said, then handed me the roll of paper and walked off, telling me to press the buzzer when I had finished! As

you can imagine I had a little difficulty with this. The result was that with the already weeping sores on my buttocks I had to lie in my own excreta until the next shift. I believe that was the origin of my being infected with MRSA.

After two and a half weeks I was moved to the Royal Orthopaedic Hospital where the operation to repair the damage to my femur was done on July 11th. I was held in the High Dependency Unit for nearly three days feeling grossly sick and unable to eat or drink. Eventually, late on the third day I was moved to the main ward and thought I felt better, but I still couldn't eat. After the pain control device had been taken away I suffered the "cold turkey" that we have heard about and seen with drug addicts. I shivered uncontrollably and cried like a baby for no reason other than I felt sorry for myself and drifted in and out of consciousness for many hours. That feeling was dreadful and I shall never forget it. The sight of the food trolley also made me feel ill, and I must thank Mary, the kind domestic Lady who served the food. She was so concerned at my refusal of food she insisted that I had the build-up drinks she would bring for me.

Three days after returning to the ward I was told that I had an infection and would need to be isolated. After the withdrawal symptoms had subsided I had the most extraordinary experience.

During the night I was lying awake listening to my per-

*"The most notable points I remember from this stay was the incredible work rate of most of the nurses, and their lack of time to stop and talk to the patients, and the absolute lack of hygiene discipline from and to the patients. "*



*“My morale was unusually low and I wondered what was wrong. I kept asking the Nurses and registrars, but was fobbed off with, ‘it’s just an infection, nothing to worry about, it will go.’”*

## Tony Field—My Story For America (continued from pg 7)

sonal stereo trying to blot out the sounds of snoring, Classic fm being the station of choice. I became aware of being above the clouds with my brother who had died in 1979 when his transplanted kidney rejected. In the last month or so of his life he became very bloated as the fluids built up in him. He told me that the consultant had accused him of not keeping to his diet and this upset him considerably as he was a man of great personal discipline.

In our surreal meeting I said to him- "I can understand why you wanted to die with all the prodding needles, tubes being inserted into you, being told what not to eat and feeling so ill." Then I noticed in the distance a white shining figure. The immediate desire was to go towards it. But John indicated a queue of people, all quietly moving that way. The atmosphere of peace and tranquility was intoxicating. I felt completely at ease and very content. I asked what was happening and he told me that the people in the queue were waiting to die. I was disappointed, I wanted to join that queue but I realised that I still had too much to do and told him so.

Then suddenly I was aware it was 5.30am and Classic fm was still playing.

Many people would say this was a dream, and I would agree with them but for one thing. The music playing I knew well and it has always been particular favourite of mine, ever since a major bank used it for a television advert. From the Chorale Prelude

by J. S. Bach, the piece is called Watchet Auf (Sleepers Awake). From this point on I began to recover.

It was a total of seven days from the operation, before my appetite returned, and it wasn't for hospital food. I suddenly craved some Danish Blue cheese and biscuits which I asked my wife to get for me. The aroma permeated the ward for some time and many questions were asked about the state of my feet! I then began to feel well enough to ask the staff to let me get out of bed. I had been horizontal for over 4 weeks at that stage. After repeated requests and repeated warnings that I would not be able to stand "You will faint because you are anaemic" they said, but finally they relented.

The big move came the next day and I was appalled and disappointed! My leg would not bend. I didn't faint and I stoically put up with the pain. Just to sit up was a joy. With clenched teeth and an unconvincing smile I insisted on sitting there for over an hour! Then I wanted to go home, but was told another two weeks of antibiotics! I finally escaped six weeks and four days after I broke my leg.

Two days before I was discharged I was told that I had MRSA which meant nothing to me other than that I had felt very ill. I had never heard of it before and I was told that it was nothing to worry about! This was a very cruel deception!

AT HOME

I noticed myself for the first time in the bathroom mirror, a malnourished, flesh hanging shadow of my former slightly overweight self. I had lost nearly three stone or nineteen Kilo's.

Six weeks after being discharged, the antibiotics had finished and it seemed that I was somewhat better. I was quite mobile on the crutches but lethargy was a problem. I could sit and doze in a half conscious and listless world for hours. My morale was unusually low and I wondered what was wrong. I kept asking the Nurses and registrars, but was fobbed off with "it's just an infection, nothing to worry about, it will go." I would force myself to do things and convince myself that I was OK but I became tired so quickly it was painful. My thigh became swollen on the scar and I pointed it out to the Doctor who was on a routine visit that day. An immediate call was arranged to the clinic. A sample of fluid was drawn off and analysed. I still had MRSA!

Two days later the swelling burst leaving a trail of blood and discharge all the way up the stairs. From that day in October 2000 until April 3rd 2003 with only a brief respite for 6 months, the sinus wept copious amounts of fluid and had to be dressed two and three times daily.

At the next clinic I asked the registrar what precisely is MRSA? and was told two of the long words: Staphylococcus aureus.



## Tony Field—My Story For America (continued from pg 8)

I then started to read about it. A bleak read, especially as a registrar told me that I had it for life. Yet another cruel deception! I spent many hours trying to find out how to get rid of it. On getting up in the morning I would squeeze my thigh until it hurt, to get out all the exudate - it might not have done much good but it made me feel that I was doing something. I was extremely angry and waging war on this bug! 10 months later it was necessary to operate again to remove the prosthesis, which had become badly infected.

A temporary spacer was put in and I suddenly felt much better! I knew that it had gone and realized just how ill I had been. After this second operation, a course of Teicoplanin was administered by injection to my backside by the district nurses. I can tell you I counted the 28 days down on that experience!

With the temporary spacer I found that I could bend my leg and I looked forward to being able to walk again. But it was not to be. After six months the scar opened and started weeping as before. It was back, so it was out with the dressings again!

It was during this period that my son returned from a backpacking trip to the antipodes. He gave me a book he had acquired on his travels called Spontaneous Healing by Andrew Weil MD. I would recommend that you all read this just to see whether you can find the inspiration that helped me to overcome this bug once

and for all.

April of 2003 saw the final operation. The spacer was removed, and the infected femur cut away to within three inches of the knee. I was then expected to lie with traction for three weeks or more while they determined whether the infection had been cleared completely. But then I found that I could pull my knee towards my chest with the 4kilos of weight attached to it and I decided that I would go out as I was - and would manage.

The thought of a prosthesis from below the knee up to the hip filled me with foreboding after reading how the bug attaches like barnacles to metal and plastic. While nothing was said to me I knew if that became infected I would lose the leg.

There was lots of opinionating and argument about whether I would have any control over movement of the leg. "It will be like a rag doll and will just drag behind you," the registrar said and he wouldn't hear of me trying to stand. I demanded to see the consultant and he agreed with me that as the infection had returned after six months from the previous operation, it would be only right to leave it at least that long, and not the six to eight weeks they had planned.

### POSTSCRIPT

The postscript to all this is that MRSA devastated my life for three years. My right leg is now 4 inches short without the femur, but somehow it works and I do have a

high degree of control over it! Due to the protracted period of the infection I was forced to give up my job. I was struck off the register of Independent Financial Advisers because I did not submit any business within a twelve month period. This has severely reduced my income for the rest of my life. However I will take my lead from Stan who I mentioned earlier, and refrain from asking- "Why me?"

I want you all to be clear about this. I know that I am privileged to be here. There are many more victims of MRSA a great number of them some 8-10 years away from retirement facing the rest of their lives on much reduced pensions and possibly in poverty. Because they will never work again. Also many more have died prematurely, leaving loved ones. The official causes of many of these deaths have the blanket titles of "Septicaemia" and "Multiple Organ Failure". Thus hiding the true scale of the infection. Despite our governments claims of increased investment, our members still report from all corners of the UK unclean wards and bad practices, it is also born out by the statistics. Hospital Acquired Infections in the UK increased over 2003-4 by 3.6%.

Our dept. of health causes confusion over the figures by quoting them as x number of infections per 1000 bed days. For those interested in figures-138000 beds available any day =50,000,000+

By its deceit and mendacity the UK governments Department of

*"While nothing was said to me I knew if that became infected I would lose the leg."*

## Tony Field—My Story For America (continued from pg 9)

Health and its advisers is now reaping what it has sown.

-Fear and mistrust of the medical profession!

To give you some idea of the scale of the scandal. Road casualties in the UK. (a population of 50million people) have held at approx 3600 deaths per year for the past few years, so as a proportion of the increase in traffic levels there has been an actual decline. With HAI's however we have had an increase year on year for the past 15 years. It is accepted by all that roads are dangerous. But who would have thought that our hospitals would today be nine times more so for MRSA and 18 times for MSSA.

Based on figures supplied by the UK National Audit Office MRSA Support can provide an audit trail and proof that MRSA and MSSA accounted for 99000 unnecessary deaths last year in the UK. Yet the Dept. of Health still say that MRSA accounts for 5000 deaths. This figure is from 1994 and is based on an estimate from America.

SO WHAT HAS HAPPENED TO CAUSE THIS SITUATION?

In two words complacency and indiscipline. The blame for this situation must rest squarely on the shoulders of senior management and politicians for cutting cleaning budgets and relaxing aseptic practices. Also senior government advisers for making statements such as this- I quote- "There is no evidence to suggest

that a clean ward is any less infective than a dirty ward".

As a patient I say - This is crass and utter nonsense. Absence of evidence does not mean evidence is absent. Just that it has not been sought.

It's for sure that his and other managers homes are cleaner than many wards in our hospitals. Shouldn't it be the other way round?

All this pain, suffering, maiming and premature death has been caused by chasing a mythical possibility of cost savings on hygiene and relaxation of aseptic techniques. Costs may well have been cut in these areas but the increase to our health budget of treating people with these infections far outweighs the savings.

MRSA Support was formed in Birmingham England in April 2003 after the City newspaper featured 13 of us who had all been infected in the same hospital over the previous 12 months. Eight of us stayed together to warn people of the dangers of going into this hospital and inform them on what they could do to prevent becoming infected.

Our booklet MRSA-A Patients Defence! was published in Sept 2003 and featured in the national press. Overnight we attracted members from all over the UK. And to date we have 600. We get on average five phone calls and 3-4 emails every day and we add 3-4 members to our list every week. Our website gets at least 40 hits a day.

### THE CYCLE OF INFECTION

The view of MRSA Support is in line with retired nurses most of who speak disparagingly of the methods of asepsis practiced today.

We see this cycle in the hospital environment- Skin scales, some of which are colonised with the bugs, shed to the atmosphere and settle out as dust. Remember 90% of dust in hospitals is skin scales! The dust is left for days on end due to ineffective cleaning and is whipped up by turbulence from natural movement and is breathed into the noses and throats of the staff and patients alike. The medics then breathe potentially infected particles from their noses, over these sites, and their hands, also dragging with their breath stream, dust particles from the surrounding air. Also it can settle onto any unprotected wound or vulnerable site.

This cycle can be broken and the bugs denied access simply by donning a face mask before the hands are washed or holding the breath during the procedure. (Can you imagine that?) We must remember that anyone in hospital is likely to have a depleted immune system, this makes it doubly important to have the highest standards of hygiene discipline and asepsis.

Also you will have noticed when forensic evidence is being collected by the police, masks are always worn to prevent contamination by their breath. The Red Cross manual of 1951

*"We must remember that anyone in hospital is likely to have a depleted immune system, this makes it doubly important to have the highest standards of hygiene discipline and asepsis."*

## Tony Field—My Story For America (continued from pg 10)

says: “It is quite apparent that these principles were followed then, and have now been abandoned.” We have been trying to work out just why these practices were stopped and one of our members, Dr. Tris Roberts a professor of physiology has pinpointed it to a statement issued by the CDC which said that the Staphylococcal bacteria could only be passed on by touch.

This was interpreted too narrowly and as a result the hospital managements thought that they could make savings by cutting the cleaning budgets and allowing the dust to lye, but as we have seen, the air is rarely still in a hospital environment.

I can tell you many stories of our members but I will mention only four today. John Lake and Ed Hopkins both lost

their legs due to carelessness over the protection of their surgical procedures. Luke Day, just 36hrs old, succumbed to the bug which got to him through the cut on the umbilical cord. Emma Malik, at 9yrs old, suffered MRSA weeping smelly puss from her ear. Imagine how that affects a young girl.

All this is so unnecessary and just for the want of thorough cleaning and a disciplined approach to treating wounds and vulnerable sites.

Our request to you is that you help MRSA Support to expose the myth that MRSA and MSSA is an infection we must accept as a risk of hospital treatment.

These and other Hospital Acquired infections can easily be avoided by returning to the Aseptic techniques and hygiene regimes

of the recent past.

Tell your friends and fellow citizens that infection prevention is less expensive than infection control and it gives a bonus. That bonus is discharging people from hospital better than when they were admitted.

It is now over two years from my last operation and only last week I had a check up. Still they are offering me a hip and knee joint and still I am refusing it. I am now clear of the bug and I intend to keep away from hospital treatment for as long as possible!

*Tony Field is the Chairman of MRSA Support Group, UK. (<http://www.mrsasupport.co.uk>)*

*“Our request to you is that you help MRSA Support to expose the myth that MRSA and MSSA is an infection we must accept as a risk of hospital treatment.”*

### Tips for preventing skin infections

Antibiotic-resistant strains of staph skin infections increasingly are spreading among healthy people, including children, other family members and athletes. Below are some ways to prevent the spread.



Wash hands thoroughly and often with soap and water.



If participating in contact sports, shower with soap immediately after each practice or game.



Wipe down nonwashable equipment with alcohol after each use.



Keep cuts and abrasions clean and covered with a bandage until healed.



Do not share items such as razors, soap, ointments and balms, towels or wash cloths.



See a physician promptly if you have a suspicious skin sore or boil.

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION

THE ASSOCIATED PRESS

### Infectious Disease Society of America (IDSA)

Prevention is so much better than cure. But for those of us who have already gotten MRSA, treatment options need to be available. The Infectious Disease Society of America has an advocacy alert on their site, located at:

<http://www.idsociety.org/badbugsnodrugs>

This organization is doing a tremendous job of lobbying for incentives for pharmaceutical companies to research new antibiotics. They can use our help. Please take a look at their site, and if you can, let your political leaders know that you support the suggestions outlined by IDSA.

## Dedicated to Education and Awareness of MRSA



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**MRSA Resources mission is to provide emotional support and education for people who are currently affected by MRSA and other Superbugs, as well as promote awareness in our communities. We have many educational resources available on our websites, and are actively working toward awareness of MRSA in our communities, both locally and nationally. We hope that you gain valuable information and support from these resources, and we would love to have your feedback on anything that you see here or wish to see.**

### **.We support these groups in their missions, and we hope you will too:**

MRSA Support Group UK (<http://www.mrsasupport.co.uk/>)

The Association to Defend Victims of Nosocomial Infections (<http://www.advin.org/>)

RID (<http://www.hospitalinfectionrates.com/>)

## In Closing....

This has been a very inspirational few months for me. As soon as my husband was at the point where he did not need constant supervision and care, I felt very moved by God to help others going through this horrible time in their lives. Through my mealy efforts to gather educational resources for MRSA patients, I met Denise, and we quickly became friends and allies. We have now officially joined together, as it truly seems that where I am weak, she is strong, and vice versa. I am very thankful that God brought us together, I believe strongly that it was done with a bigger purpose in mind.

I hope that you have allies in your life that are helping you battle your infection. Support is so important—sometimes you don't miss it until you don't have it. I

know that my family has had problems in the support area due to some being afraid of MRSA and unwilling to educate themselves. This is a shame, and is often preventable. One thing that you can do is to talk to your friends and family members openly about MRSA, and how they can avoid it, as it is easily avoidable in the community setting. Personal hygiene is key.

Fall is football season so be sure and let your children and friends who are involved in athletics know how very important it is for them to thoroughly disinfect their equipment after use, and to not share equipment. This is not a time to indulge in elective surgery either. If you haven't, go back and read Tony Field's story, paying close attention to his decision to refuse a prosthetic device in his leg.

We hope you have enjoyed this first issue of the MRSA Resources newsletter, and although we hope and pray and work towards elimination of MRSA altogether—and therefore the need for this newsletter - we look forward to doing our part to support you, educate you and help you through this newsletter, our web sites and in any other way that we possibly can in the future.

God bless you and your families!

Til next month,

A handwritten signature in red ink that reads "Christina".

Christina Jones