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| Posts |
| 489.I am starting on methotrexate and Entyvio. Any advice with these two medications? I was on Humira and it caused demyelination on my cerebellum, so the doc said Remicade is not an option. |
| 552. I recently started remicade, I'm due my 3rd infusion 27th august. This medication is kinda now a 'last resort' as iv become extremely intolerant to past medications such as humira etc I know it's only early days and this remicade 'was' shoeing great promise as it's reduced the crohns pains, lack of tiredness, sore joints etc but in the last 3 weeks my eyes have become so sore to the point they are currently swelled, extremely bright red, very sore, stinging and itchy! They just seem to keep flaring up and it's becoming a real issue as it's getting me down aswell as being very uncomfortable. Iv been to the doctors numerous of times and will be ringing them again this morning but everything prescribed dosnt seem to be helping. Anyone else experienced anything simular? Xx FpSD eyes bright reg |
| 913. Has anyone had their child treated with Remicade? My 7yr old girl was just diagnosed with Crohn's last year. She is on methotrexate and sulfasalazine. Her calprotectin numbers is rising again. She will get a mild dose of steroids. If this does not work, remicade is our next step. I need some advice and support. It is so hard for me to think and grasp all these. Remicade is scaring me. The side effects etc. :( |
| 5264. If any of you have a roku device. look at the new show or channel it on new on my box and i added it called talentyoushouldknow15 or Talent You Should Know watch episode 1 the have a lady on that blast and talks about the nightmare of prednisone in really funny way may me laugh glad i am not the only one with the problems of prednisone it problems. it will give a good laugh. Hope every having a good day today I have UC for 10 year and was on prednisone now i am on Remicade much better. |
| 6380. My name is Heather and I have been suffering from Crohn's disease for 5 years now. My doctor has recommended I start Remicade. We tried to join the remistart program to help pay for the drug. But the program insists I pay $500 up front to start the drug. I simply can not afford to pay that. Does your organization have any program to assist in these types of situations? Mrs. Heather Lyle |
| 6699. Hi all. Am new to this forum. Back story on me. I was diagnosed with ulcerative colitis when I was 19. Had severe pain, bleeding and constantly going to the bathroom. After I finally got it under control I was in remission for many years, no drugs at all and life was just fine. Had a minor flare about 5 years ago but got that under control. Once November last year came about my symptoms once again showed up. Started with bleeding, then frequency, then pain. Got put back on asacol and prednisone but did not make a difference. Had a full colonoscope done in February and was only localised to only 4". Two days after that my symptoms got really bad. Severe pain and bleeding all up my left side and lower abdomen. I got put on colifoam as well as pentasa on top of the other meds.... Still continued to get worse. Finally in April I was admitted to hospital where for a week the team at my local hospital really were grasping at straws as to how to get it under control. I was then transferred to another hospital with a gastroenterologist specialist team where they put me on hydrocortisone IV every 6 hours for 10 days. It managed to slow everything, but every now and then slight pain. They took me off and switched to prednisone 40mg but started bleeding again. I forgot to mention in this time I had many x-Rays and two sigmoidscopes. It had turned out to be well over a foot!! They couldn't go in any further without causing damage as it was so severe. I had the surgical team discuss getting my bowels removed and it really scared me. I'm 33 and had two kids under 3. I want to be healthy for them. So last resort they put me on infliximab/remicade before pulling my bowels. That was almost two weeks ago and seems to be working. No pain, no blood and frequency is down to 3-4 daily. I have my next round in a few days, then 4 weeks after that. Also continuing taking prednisone and tapering that off, but taking 2g pentasa orally morning and night as a maintenance drug... I really hope that this remicade will continue to work as it seems to be a life saver for me. I haven't felt this normal in over 6 months. |
| 9642. Anyone have experience with being on Remicade at an early age? My son's Dr. just ordered him to receive infusions... And I am really scared/nervous since my son is only 9. He is a trooper and had adapted well since diagnosed at age 5, and is excited for the 4hrs of slurpees and video games that come with the infusions... I think I'm more nervous than he is! Is this the last chance for treatment care since resection is not an option? I always heard Remicade was the last option, and I am nervous what will happen in the future if his body gets used to this medicine... |
| 11357. For the ones who take 6mp should they stay on it for all over their lives like Remicade or can they switch for another medication or can they cut it completely if they get better any ideas thank you!!! |
| 23554. I've had crohns for 20 years. just keeps getting worse - first it was prednisone and pentasa for 10 years then after a hospital stay I got remicade for a year then back to prednisone for a couple of years. Then Humira for 3 year until the disease broke through and I ended up with a resection in 2014. Just had a colonoscopy today (ya it took a year because of crappy Obamacare) and now classified as severe crohns... back on prednisone and pentasa and after 6 weeks going to a new injectable called something like "sinsa" (sp?). Has anyone heard of this new med that is supposed to be better and have less side effects than humira???? TY |
| 23558. Los Angeles Lakers rookie Larry Nance Jr. overcomes Crohn’s Disease on path to NBA Five and a half years ago, I was diagnosed with Crohn’s Disease. The diagnosis never feels as dramatic as the symptoms, so let’s rephrase: Five and a half years ago, I was bleeding internally. I couldn’t eat. My gut felt like a scientist had drugged me, laced a long stretch of barbed wire through my large intestine and was steadily dragging it forward. I couldn’t go anywhere because I needed constant access to the bathroom. I had lost 40 pounds. I didn’t know what was wrong, and ” seeing the sheer volume of blood I was losing ” I was terrified to find out what was happening. Crohn’s Disease is an auto-immune condition that is becoming increasingly prevalent in Americans. Essentially, your body decides that your colon is a problem and tries to rid you of it using ulcers. There’s no cure, but it’s not life-threatening (assuming it’s treated), and with certain drugs, your body can be fooled into thinking that your colon is necessary. All you have to do is find the right drug. It took nearly a year, but we found my right drug. ””- œHow great is Remicade? I asked Los Angeles Lakers rookie Larry Nance Jr. on Tuesday. Nance Jr. rolled his eyes backward in agreement. œOh my gosh, he said. œI can’t imagine there’s a better drug than that. It’s amazing. It really is. You’ll have to excuse us for gushing, because you need to understand: Remicade is seriously so great. It’s an infusion given once every 6-8 weeks, depending on how fast the disease flares up. I get it every six weeks. Nance Jr. gets it every seven. When I first received Remicade, I was midway through my third Crohn’s flare. My weight, which had fluctuated through a 70-pound cycle, was back down to 30 pounds below normal, and once again, I was bleeding profusely. A day after starting Remicade, the bleeding ” which had been happening for several weeks ” stopped. Two days later, the pain was gone. Three days later, I was released from the hospital. A week later, I was nearly back to normal. When Nance Jr. first received Remicade, he was a scrawny teenager ” 6-feet tall and 130 pounds. He had been sleeping constantly and was always lethargic ” coming home from school and immediately heading to the bathroom. He couldn’t eat. He couldn’t leave the house. He couldn’t live. œI hated basketball, I hated soccer, and those were my two loves at that point, Nance Jr. said. œMy parents were like ˜Something’s not right. Our kid is short and hates sports.’ Those attributes aren’t always symptoms, but when your father is 6-foot-10 former NBA forward Larry Nance, being short and hating sports aren’t likely to manifest naturally. From seventh grade to sophomore year of high school, Nance Jr. suffered ” confused, scared and hopeless. Pain from an injury makes the injured person pine for health. Chronic pain makes you forget what being healthy was like. Nance Jr. was diagnosed with Crohn’s Disease at the age of 16. Two weeks after his diagnosis, he received his first dose of Remicade. Shortly afterward, he began eating and his malnourished body began to flourish. Today he’s 6-foot-9 and 240 pounds of solid muscle. He’s explosive, even among professional athletes. He was the 27th pick in the 2015 NBA Draft, and he loves basketball. It’s funny what the right drug can do for you. œ(Remicade) was like Popeye’s spinach for me, he told me, laughing. I nodded enthusiastically. Two years ago, I switched doctors. The new physician saw how well I was doing and wondered if I was in remission. He took me off Remicade to see how I would fare. Three months later, I was back in a familiar hell. I couldn’t ever be more than a short run to the bathroom. I was bleeding, and the barbed wire was back. The doctor was hesitant to put me back on Remicade and tried multiple drugs, none of which worked. He finally relented and restarted my Remicade. A week later, I was back to full health. Nance Jr. is 22 now ” a man who, as long as no one slips a peanut into a brownie, thinks about his health as often as a normal person. œOnce we got (Remicade), it was like ˜Look at all this free time I have now,’ Nance said. œNow I can go work on basketball, I can go work on soccer, I can go be a kid. That’s what changed mentally for me. I just got what I had to have. œThe second I got my first dose, I was back on the basketball court, back on the soccer field, killing everybody. I was starting to grow. I was thriving, because my system was so backed up and slow. Once we kick-started it, I was gone. ””- I’m a reporter now professionally, which means I’m not supposed to root for anyone, but I’m rooting for Larry Nance Jr., and as you might imagine, it has nothing to do with basketball. That said, I like his game. He recognizes what the Lakers need from him ” energy, rebounding and athleticism. Players like Nance Jr. generally carve out long, productive professional careers ” the kind of careers that make people look back say œWow, the 27th pick? He was really good value. The Laker fans at Las Vegas Summer League ” who, incidentally, are everywhere and are Legion ” like him already as well. œI ran over in the corner and there were people on the sideline who were like ˜Nance, dunk on someone, dunk on someone, dunk on someone,’ he said. œOf course I’m like ˜Yeah, okay, I’ll try. I’ll do my best.’ He doesn’t think about Crohn’s disease anymore. He doesn’t have to. œI just have to stay on top of medication, he said. œIn terms of it affecting me, it really doesn’t. That’s why I’m rooting for Larry Nance Jr. He’s living out every kid’s dream playing for a glamour franchise in a beautiful California city. He has the lucrative guaranteed contract of a professional basketball player drafted in the first round. He is no longer a scrawny teenager ” he’s a heavily muscled 22-year-old. Saddled with a disease that makes it easy to lose hope, Larry Nance Jr. is winning.FnDSn |
| 23748. Tanya Sweeney-Crosbie 21 May 22:41 I am not sure if this is the right forum, but I have a question. I have fistulas and was on remicade. I am 8 months pregnant and took my last dose over 8 weeks ago (to ensure there is no drugs left in my system for at least 3 months prior to delivery). Like many immune issues, pregnancy has really helped my crohns disease. My question is this. If my fistulas are healed, could it be possible that I wouldn't need to take the remicade again? Should I wait to see if they come back before I jump back onto that drug? I am having a csection because I have a jpouch and I am supposed to have an infusion while I am still in the hospital. BUT I feel as though if I can get off this ridiculously expensive drug, I want to. Any thoughts/advice would be greatly appreciated. Tanya |
| 24133. I AM ABOUT TO START REMICADE, HAS ANYONE EXPERIENCED HAIR LOSS WHEN DOING THIS? FnSDloss hair |
| 24222. A new way to treat Crohn's disease with oral medication in the pipeline A new drug is in the pipeline for Crohn's disease treatment that is expected to move to a third clinical trial in the near future. The drug, known as GED-0301 or Mongersen is an antisense medication taken orally that has been well tolerated and induced remission in sixty-five percent of Crohn's disease patients studied. The medication could replace injections for treating IBD. The drug manufacturer Celgene (CELG) has released results of an experimental Crohn's disease drug, GED-0301 that could eliminate the need for injections currently used for IBD treatment, IBD drug leads to high remission rates Celgene reported the drug, also known as Mongersen, induced remission of Crohn's disease at two-weeks in sixty-five percent of patients studied compared to just 9.5 percent for placebo, which is higher than rates seen with the injectable drugs Remicade or Humira. The results were presented at Gastroenterology week in Vienna this week and released by the drug company.Celgene will begin a phase-3 trial of the Crohn's disease drug this year. Mongersen is known as an antisense drug. Researchers have discovered blocking certain proteins in the body could change the genome that drives Crohn's and possibly a variety of other diseases. Studies of antisense drugs for Crohn's disease show that high levels of a compound known as Smad7 interfere with the immune-suppressive activity of transforming growth factor (TGF)-Ž²1. The result is inflammation. Crohn's and UC treatment is aimed at quelling inflammation that in turn helps prevent complications that can lead to surgeries and repeated hospitalizations. In the phase one trial, researchers tested levels of circulating cytokines that measure inflammation. Mongersen reduced the number of cytokine expressing cells.The drug was also well tolerated. "GED-0301, a first-in-class oral antisense therapy, has the potential to change the treatment landscape for Crohn's disease," said Scott Smith, President, Celgene Inflammation and Immunology in a press release."Celgene is excited to pursue the clinical development program for this novel therapy in phase III trials in the near future." The need for new therapies for Crohn's disease is highlighted by failure of anti-TNF agents that often fail to induce remission of IBD. Celgene's drug GED-0301 or Morgensen is the first of it's kind. |
| 24378. Hi, i just found out I have Crohns disease and its a little overwhelming. I was told I could go on Humira, Cimzia or Remicade. And I should research these and see which ones sound better. IM sorry!! WTH?? When did I become a doctor? Can anyone help me with this, that has Crohns? Which medication is better or least side affects? Or information at all? |
| 24828. Drug Treatment Choices Patients using anti-TNF specialty drugs to treat RA and Crohn's aren't aware of treatment choices Patients using anti-TNF specialty drugs to treat RA and Crohn's aren't aware of treatment choices A survey of patients using anti-TNF drugs to treat chronic inflammatory conditions, such as Crohn's disease and rheumatoid arthritis, showed that less than half had discussed alternative treatment options, such as infusion or injection at home, according to a study published today in American Health & Drug Benefits. The survey, developed and administered by HealthCore, an outcomes research group and independent WellPoint subsidiary, was used by the national health insurer to develop a program to reach out to members of its affiliated health plans and inform them of their options. Generally, infusion anti-TNFs are administered at a hospital outpatient or physician provider site but there are also options for administration within the home. Some injectables can be self- administered at home. Prior studies have shown that there aren't clinical outcome advantages to infusing specialty drugs at a facility compared to home-based infusion. "Making these kinds of choices about where their drug is administered and the method of receiving their drug can be empowering for the consumer," said Dr. Alex Ruggieri, co-author on the study and WellPoint medical director for pharmacy services. "The member stories have been illuminating. At least one member saved himself the inconvenience of a four-hour round trip every few weeks when due for his infusion. For some, these choices could make a difference in their overall annual out-of-pocket expenses." Hospital infusions can cost much more than those performed at home or in a physician's office. For example, WellPoint data from its affiliated health plans in 2013 shows that the average amount for intravenous infusion of Remicade at the hospital is about $7,300, while intravenous infusion is about $3,800 in the home and $3,600 in the physician's office. Survey participants were asked about their use of anti-TNF agents, locations of administration, preferences for IV or self-injected therapy, interest in anti-TNF home therapy options, and their physician's role in their decision-making process. |
| 27043. Dear lawmakers currently attempting to shut down Obamacare, My name is Kendall Brown. I am a 26-year-old, college graduate with a full-time job. I am the Executive Director of a statewide arts organization in Oklahoma and the organizer of a monthly event in Oklahoma City that is open to the public and provides entertainment to thousands of people each third Friday of the month. And I am dying, because of the political games you are playing right now. You see, I was born with Crohn’s Disease. This didn’t happen because I ate unhealthy food, or because I smoked, or because of any of the other reasons we use to victim blame sick people and justify not giving our countrymen adequate health care. I became severely ill beginning in the third grade because I won a genetic lottery that left me with a disease that would quickly drop me to 87 pounds, render me unable to walk at times, and nearly kill me twice. For the first 26 years of my life, I was lucky enough to have insurance to help foot the bill of my care. Now, don’t get me wrong, it wasn’t easy. I have very clear memories of my childhood involving my mother at the kitchen table, pouring over our finances, attempting to find it in the budget to purchase my daily handfuls of pills at often well over a dollar a pill...with insurance. For a brief period in college, following my birthday that year, I was removed from my mother’s insurance. You see, some semesters I was so ill that I could only complete a small amount of hours at a time, meaning I didn’t qualify to remain on her insurance by sheer virtue of my college enrollment. That brief period, in which I could afford nothing but limited student health insurance, left me with thousands of dollars of medical debt I may never be able to fully pay off. Luckily, thanks to the first steps of œObamacare I was able to get back on my mother’s insurance until my 26th birthday. Right before my 25th birthday, I had major surgery to remove nearly two feet of my intestine. Without that first bit of the Affordable Care Act, I could not have gotten the surgery. And without the surgery, I would have died. But I lived. And shortly following my surgery, I went on to get hired at the Individual Artists of Oklahoma, where I am the Executive Director. Through my position there, I have been able to offer community programming to thousands of men, women and children in my state over the past year. I don’t tell you this to brag on myself. I tell you this because I truly, fully believe that had I died back in April of 2012, rather than have surgery, my city and my state would be worse off without me. Now, for the past year, I have been without insurance to cover the cost of my Crohns-related medical care. I am the only full-time employee of the organization for which I work, meaning I can currently be denied health care coverage for my œpre-existing condition. And denied I have been. Following my surgery, I was put on Remicade, a form of chemotherapy to manage my Crohn’s Disease. It is not an ideal drug (it comes with many of the side effects you’d associate with œchemotherapy) nor is it one that will work forever for me. But it works for now, and hopefully will continue to do so until there are more options available to me. But this past March I was turned away from the infusion clinic I attended, as my new health insurance had decided they would not pay for this life-saving medicine for me, and I could not foot the $15,000 per infusion bill. The last six months have been filled with frantic searching for methods in which to receive my infusions. For a temporary period, I was able to receive infusions in the same clinic where our state prisoners receive treatment (and if you want a humbling experience, try getting chemo next to a man with one leg in prison scrubs and handcuffs.) But following a kidney infection, during which I couldn’t receive treatment, I have been unable to get back into the clinic, largely due to budget cuts that leave them with too many patients and not enough time. I don’t tell you this to make you feel sorry for me, Mr. or Mrs. lawmaker. I tell you this because I am tired of being reduced to a number, a statistic or, even worse, being described as a freeloader that wants to live off of the government health care teat. I tell you this because if you defund Obamacare, or delay it even for one year, as you are debating today, then this will be my last letter to you. I will be dead before my 27th birthday. If you think that my life, and the lives of thousands of other people like me have no value, then by all means, delay the ACA. But before you do so, I’d like to invite you to hear stories from others like me, or, if you find yourself in the great state of Oklahoma, come meet me. I’d love to show you around and buy you a cup of coffee -- and to introduce you to the woman you are killing. Sincerely, Kendall Brown Originally published on okc.net What do you think of this? |
| 27595. Disease = DyingSeas Hello my name is Hilar Siveri, i have had Crohns disease for 8 years, and I NO LONGER REQUIRE ANY MEDICATION FOR IT!!! :D Also i am able to eat candy, chips, cookies, etc. and my stool is fine! Since I have started restructurizing filtered H2O 4 months ago, i have gained my energy back, and i am feeling better then ever! The "doctors" are not your friends, they don't care for making cures for anything, they are just blind program followers that are trained to feed of you like parasites! I have been on remicade for 2 years, and i have noticed every time i got an infusion it felt refreshing like drinking lots of water! 4 months ago i made a device that restructurizes water molecules, by mimicking the natural flow of rivers, and when you add Neodymium magnets that are repelling each other and you pass water trough it, it charges the water moleculars even more which will give you more energy when you consume it! And today i can safely say that i no longer require drugs for my condition! And I want you to do the same, in return you will help me clean up the medical industry by not support these so called "doctors" that are nothing more than drug dealers! I am not sure how it works for other conditions, but you should try it anyways! And how it works is pretty simple once you have the device made for your selves, you constantly drink lots of restructurized water, which will keep on flushing out your system, and rite away you should feel a tingeling sensation, like getting high on H2O! And slowly you should get better from it! You are suppose to be made up of 80% H2O at all times!!! This device was based on Dr. Emoto Masaru documentaries and Clayton Noltes device for structurizing the molecular of water! This device will improve your mind, body, and soul! And i am giving it to you for free! This is also how Jesus turned water into wine! You will know what i mean once you try it! Cheers! HS FpSDrefreshing |
| 28151. Inflamed and Untamed Welcome! My name is Sara, and I don't have a large intestine, but I DO have a large amount of passion for spreading awareness about Crohn's disease and ulcerative colitis! Diagnosed with UC: 1996 J pouch surgery step 1: july 18, 2008 J pouch surgery step 2 and adhesion removal: September 10, 2008 Diagnosis changed to crohn's: June 17, 2011. Tried too many meds that failed, currently doing remicade infusions and methotrexate injections. Hello, my name is Sara and I have Crohn’s Disease! \*\*This post is edited. It was originally from the HAWMC (that I never completed) where I was asked to introduce my disease to people who don’t know about it. Updating and sharing again! 1. My name is Sara. I do go by the name Sadie though often now in my real life. It all started at my job where there were 5 other people who had the name Sara. They call me Sadie there which is a nickname of Sara. Now we have six people there with my name! Other names I am commonly referred to are: Ringer, Ringo, Sara Sally Ringo Raphael, and Squirt. You can thank my mom for that last one. <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/1.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/1.jpg" alt="1" width="500" height="419" class="alignleft size-full wp-image-782" /></a> Hello. Here is my face. Now you know what I look like. Well what I look like in bright lights and makeup, anyway. 2. I have Crohn’s disease (i’ll get to that in a bit). I also have a j-pouch, a motility disorder, and autoimmune arthritis. I suppose I could tell you the little things like I currently have a hernia and gallstones but those are just the little details. 3. I work at a salon. And by work, I mean I go there when I am not in the hospital or not out for long periods of time due to my disease. I’m sure you other health activists know how that goes. My boss is amazing for that, and I found a real passion in what I do by chance. I have my disease to thank for that! I do nails and makeup there and it is fan-freaking-tabulous! I also manage the social media of the salon. I’m a hard worker, I always have been and I always will be¦unless something is preventing me from doing so. 4. I have an animal problem. No seriously, I am pretty sure if people were not around to stop me that I would have 4 dogs and 7 cats by now. Luckily someone is always there to stop me¦most of the time. That is how I wound up with my big German Shepherd dog, Scout. I went to the Humane Society to maaaaaybe get another cat. I felt like my cat, Ludacris, needed a kitty friend so I went there to scope out the felines. I took a wrong turn and wound up near the dogs and that is when I spotted a 7 year old German Shepherd who had bandages on both legs and a head cone. He also came with anxiety meds and prednisone. I came home with him! Oh btw, I have never had a dog of my own before then. There are 3 horses and a donkey for sale right now at the Humane Society¦ 5. I have an incredible memory. I love to read. I LOVE the Harry Potter series books (movies are okay but the books¦omfg) and I am convinced I am in the house of Ravenclaw. If you are rolling your eyes right now then it’s obvious you’re a muggle. Unicorns are fun. I like to eat cake. Sunshine makes me happy. I have the imagination of a 5 year old but at the same time I am a very old soul. 6. I was a dancer for a huge portion of my life and then went on to teach and choreograph. I had competitive dance students that went to local and national dance competitions. Think Dance Moms except I wasn’t a big and mean teacher. I was small and loud! While I worked as a dance teacher I had a second job as a cake decorator. I was the lead cake decorator for many years in the bakery. 7. I am terrible with technology. No for reals you guys. It’s a wonder I know how to operate this blog. I learned how to edit videos in the past year and use the easiest program for everything. I am apparently good at fooling people because everyone thinks I got skillz! Y’all, I can’t even operate my remote control! I still don’t understand google analytics fully and have no idea how many people actually read this blog. I like to stay in the dark and pretend like I get thousands of hits a day. ;) 8. I have a chauffeurs license. I could drive a limousine, taxi, or a small school bus if needed. 9. I love snakes and all cold blooded animals. At one time my brother and I had 15 pet snakes because the snake we had had babies! 10. My favorite kind of food is tied between Thai, Indian, or sushi. I love socks but hate to wear anything on my feet. I have a biggest heart but it’s hard to knock down the walls I’ve built up to get to it. I love laughing, I love to learn, and I really love to travel. I hate cold weather. I don’t understand hatred, violence, or the evils of the world. They can get me pretty down. All I want to do is leave my mark on this world and make it a better place for at least a few people and in return all I require is feeling happy, safe, and content. I never want to stop learning because once you stop learning you stop growing. I also never want to stop teaching. I’m pretty fricken silly most of the time. Okay, WEGO told me to introduce my health condition to you all. So now here we go for real: Hi, I’m Sara, and I have Crohn’s Disease. I don’t have any of my large intestine or rectum left (ewwww, she just said rectum!). Did you know you could live without your large intestine? I didn’t until I got sick. Fun fact: Your large intestine and your colon are the same thing. I use the words interchangeably on purpose because of that fact. If you didn’t know before, now you do. I have no colon. I have no large intestine. Same thing. Ba-da-boom, ba-da-bing! <”-I just wanted to say that. <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/2.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/2.jpg" alt="2" width="500" height="515" class="alignleft size-full wp-image-783" /></a> (I like to make IV’s look fashionable. hahaha) I have a J-Pouch. It’s pretty cool you see, I’m kind of like a marcupial except I don’t carry my babies in my pouch. I carry my¦. nope. Not going there. So as I said, I don’t have my colon. Instead the end of my small intestine has been reconstructed and turned into an internal reservoir and is attached to my anus (Crohn’s disease is the sexiest of dem all!) so that I can use the bathroom just like everyone else. To get my j-pouch I had to have two major operations that came with a lot of pain and complications. A normal persons insides look like this: <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/3.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/3.jpg" alt="3" width="500" height="643" class="alignleft size-full wp-image-784" /></a> Mine look like this: <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/4.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/4.jpg" alt="4" width="493" height="335" class="alignleft size-full wp-image-785" /></a> Like I said, sexiest disease of them all! To read more about my j-pouch and what it is you can read this blog I wrote: http://www.inflamed-and-untamed.com/post/24890754880/what-is-a-j-pouch \*So here is what you need to know about Crohn’s disease. A lot of people have the misconception that it is just like IBS. If I can get you away from one thing it would be this. Crohn’s disease is an inflammatory bowel disease. IBS is Irritable Bowel Syndrome which sucks, but is a much less serious condition. Another misconception is that it has everything to do with stress and diet. Listen peeps, if I could have saved my large intestine by changing my diet and controlling my stress, you better believe I would have. This is an autoimmune disease, just like Lupus, Rheumatoid Arthritis, and all the other autoimmune funtime body games. My disease attacks my digestive system but it also has what are called œextraintestinal manifestations". Meaning a lot of people with Crohn’s disease also have issues outside of the digestive system like arthritis, eye problems, skin problems, liver problems, and so on. I have arthritis that can often be debilitating. It’s awesome being young and feeling old. No, no it’s not! Crohn’s disease can attack your mouth, esophagus, stomach, small intestine, large intestine, and rectum (I am finding every excuse to use the word rectum). When I am sick my remaining intestine becomes inflamed and starts bleeding. It’s not uncommon for people with my disease to need blood transfusions from bleeding internally. I have received some blood transfusions myself. This bleeding also causes a person to become anemic which causes extreme fatigue and so on! When my intestine is bleeding and inflamed it hurts to eat. It hurts to eat ANYTHING. Sometimes it even hurts to drink water. I also don’t absorb nutrients well during those times and lose weight rapidly. That also contributes to the major fatigue I often feel. There have been times when I have not eaten any food by mouth for weeks or months at a time. I am put on something called TPN which is nutrition that is given to you through a PICC line. Sometimes patients are put on this to give the bowel a œrest". Sometimes patients are put on it because they are not able to absorb nutrients when they are so inflamed inside that their intestine isn’t able to absorb what they are taking in. Sometimes we are put on it because of something called Short Gut, which means that so much of the digestive system has been removed through multiple surgeries that they now don’t have much of it left. There are a number of reasons why Crohn’s disease patients are put on TPN. Surgeries are something a lot of us are faced with. Sometimes the whole colon has to be removed or sometimes patients have portions of the small and/or large intestine removed. For patients with Crohn’s disease the likelihood of the disease coming back near the portion of digestive tract that was removed is high, therefore multiple surgeries are sometimes required over a lifetime. <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/5.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/5.jpg" alt="5" width="500" height="375" class="alignleft size-full wp-image-786" /></a> (After a surgery) Some patients experience painful blockages. I have been hospitalized many times for them and have had a surgery to resolve one. Blockages can occur because of something called strictures, which are a narrowing in the digestive system caused by scar tissue. The scar tissue is the result of periods of inflammation and healing over and over which hardens the intestinal wall and it thickens. Blockages can also be caused by adhesions due to surgery and a number of other factors. Sometimes these blockages heal on their own, other times a patient requires hospitalizations for pain medications and fluids or nutrition until it passes, and sometimes surgery is required. Some patients experience fistulas. This happens when an ulcer in the bowel penetrates through and creates a tunnel from the digestive tract to another area in the body. This tunnel can lead to the skin or to other organs. Sometimes an abscess occurs due to the fistula, which is a very serious infection. A number of different medications are used to treat Crohn’s disease. I go to the hospital every 7 weeks to get an infusion of a drug called remicade. Remicade is a biologic and works like chemotherapy to suppress the immune system. I also inject myself with methotrexate, which is a chemotherapy that also suppresses the immune system. Because of this I have to be extra cautious around sick people. I also worry about the potential life threatening side-effects of these medications. Steroids are very common in my community, which also have horrible side-effects. Other patients use different types of anti-inflammatory drugs. A lot of times finding the right medication for the patient is a guessing game. We are all a bit different and respond differently to treatments. What is even more confusing is that a medication can work for a patient for a long period of time and then just stop working. Some patients don’t respond to any medications they try, and some patients choose to not take medication at all. Symptoms vary from patient to patient. The most important thing to understand is that every Crohn’s disease patient is different. Some of us have the disease very mild, others very severe, and everywhere in-between. You might meet a Crohn’s disease patient who has an ostomy. This is often a life saving surgery where the intestine sticks out of an opening in the abdominal wall called a stoma. The patient has no control over the things that move through their digestive system and therefore a bag has to be attached to the stomach around the stoma to collect waste. This is not gross and these people are not to be feared. Take a look at my sexy friend and fellow Crohn’s disease advocate Jess Grossman who is working so hard to squash ostomy stereotypes. She’s hot and she shits in a bag. So what! <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/6.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/6.jpg" alt="6" width="402" height="604" class="alignleft size-full wp-image-787" /></a> It’s not uncommon to experience anxiety and depression from living with Crohn’s disease. It’s exhausting both physically and mentally! Medications cause changes to our bodies such as weight gain, weight loss, hair loss, moon face, psoriasis, acne, arthritis, and so forth. These changes to our bodies are hard to handle because we have to take the medications and have no control over the effect they have on us. Surgeries alter the way our bodies look and function which is a major adjustment. Frequent hospitalizations and uncertainty in our life plans cause major anxiety and fear of the unknown. We often feel embarrassed of our disease or symptoms and isolate ourselves. When we are bleeding internally or inflamed we become tired and our bodies are working extra hard fighting a disease. That, medications, and other things make life with Crohn’s disease often exhausting. We may cancel plans or seem like hermits at times. The cool news is some patients respond to treatments or surgeries well and are able to live happy and full lives. Others do not. It’s all a wide range of how the disease will affect a patient. This is just a liiiiiitle bit about life with Crohn’s disease. That may have all sounded scary and depressing (truth is some of it is) but my disease has taught me a lot of life lessons. All I can do is do my best and keep putting one foot in front of the other. I look at life a lot differently than my peers and I think it’s a blessing. The thing I want most people to know is that I don’t want pity and I don’t want you to be afraid of me. I’m pretty cool - I’m funny, smart, and interesting (hopefully) and I make a pretty great friend. I just also happen to be sick. So that’s me and my disease. Now I am off to meet all of you! -Sara |
| 29032. this is for every crohnies out there that`s on Remicade - how long are you in remission? |
| 30106. Hi i have crohns disease,and am starting remicade next week any advice |
| 30379. I've had four bowel resections and had five years of remicade and am now on humira. Are there any statistics on long term use of either of these medications? |
| 31168. Hello, I am a 34 year old woman that has been living with crohn's for over 12 years now. I've read through a lot of the postings on here and know how almost all of you feel. Sad part with me is, I'm allergic to almost every medication that could make me better. I've been on asacol, pentasa, remicade, immuran, and now on sulfasalazine. Asacol and Pentasa don't work on me and I'm allergic to immunosuppresants and also Remicade/Humira. My GI is baffled on how to get my disease under control and so am I. I've been on steroids pretty much for over 2 years straight, and that's not good for anyone because of the side effects of long term use. I've had 3 surgeries, having a total of over 6 feet of intestines removed, and the first surgery I also had a mass larger than a grapefruit removed from my gut as well. If anyone knows of a medication that could possibly work and is not an immunosuppresant please let me know. My GI is even talking about sending me to another state to see a different specialist to see if they can figure something out. There's even talk of doing another surgery and I just had my last one in July 2012. I began flaring up after this last surgery not even 4 months after surgery. |
| 31465. So anyone here with Crohn's Disease ever been prescribed Remicade before?? My doctor is putting me on Remicade I.V. Injections hopefully this week or I'll end up hospitalized again without it.??? |
| 31982. Crohn’s disease a daily battle for Elora girl Kaylyn Heine, a dancer with the National Ballet, has had to deal with the added challenge of being diagnosed with Crohn's disease. David Bebee/The Record ELORA ” Starting when she was just two, Kaylyn Heine loved to dance. When she became too sick to do what she enjoyed most, her mother knew something was really wrong. œShe dances. That’s her thing and she couldn’t, said Shannon Heine. But now, after a tough couple years struggling to get healthy again, 13-year-old Kaylyn is back where she sparkles ” on the stage. This holiday season she is dancing in Canada’s National Ballet School’s production of The Nutcracker in Toronto. The Elora girl has trouble putting into words everything she likes about dancing: œIt’s fun. But for a while Kaylyn simply didn’t have the strength. She was 10 when she first started suffering severe digestive issues, including terrible cramps, multiple urgent trips to the bathroom and bleeding. Embarrassed to talk about it and unable to explain how much pain she was suffering, her doctors didn’t worry much about it at first. Months passed, her weight dropped and she was too sick to make it to school many days before an appointment was booked to see a specialist at SickKids. œKaylyn didn’t make it to the referral. She ended up getting worse and worse, Heine said. When she got a very high fever ” prompting her mother to check with different thermometers because she thought they were not working ” Kaylyn was taken to the Toronto hospital’s emergency department and admitted. œThe pain she was in was unbelievable, Heine said. œShe would cry, it was so brutal. œIt hurt a lot. I didn’t really know what it was, Kaylyn said. Testing discovered Kaylyn had Crohn’s disease, a chronic condition of the digestive tract that along with ulcerative colitis is known as inflammatory bowel disease. Common symptoms are abdominal pain, diarrhea, intestinal bleeding, nausea, weight loss and lack of energy. The disease affects 200,000 people in Canada, which has one of the highest incidences in the world. Finally getting a diagnosis eased the family’s anxiety. œI was relieved because they’d be able to treat it, Kaylyn said. œThey can’t do anything if they don’t know what it is. But finding the right treatment for Kaylyn is turning out to be a challenge. When the first medication didn’t work after a couple months, she was switched to intravenous doses of the biologic treatment Remicade that proved quite effective although that took six hours every few weeks. Kaylyn was well enough to dance again. œShe was in remission, which was fantastic, Heine said. Being out of classes at Elora Public School so much that first year of her illness was tough on Kaylyn, an eager and accomplished student who became depressed. œThey just want to be normal ... They just want to be doing what everyone else was doing, her mother said. Now Kaylyn is in a school board-sponsored home instruction program that can be flexible with her illness while keeping her on track with the curriculum. For a year and a half the medication worked. Then this spring Kaylyn began suffering severe headaches lasting days after treatments, then her vision began to be affected. For months she was sick and ended up in hospital again. œShe couldn’t do anything. She just sat there in pain, Heine said. Two more medications caused worrisome side-effects, including affecting how well her liver functioned. Once that is back to normal, Kaylyn will start on another medication within the next few weeks that can be injected at home. œWe’re really hoping, hoping, hoping that it works, Heine said. Seeing Kaylyn on the stage will be a sweet moment for her parents Shannon and Mark and older brother Taylor, who also feel the strain of her serious illness. Her mother cut back on her job as a music teacher to care for her daughter and the costs add up with numerous trips to the hospital and other expenses. œIt’s hard and they talk about that when they’re diagnosed, Heine said. Thankfully they had coverage for the costly Remicade treatment and Kaylyn became an ambassador for the Canadian charity Robbie’s Rainbow that helps families who can’t afford expensive drug treatments not covered by private or provincial health plans. Kaylyn, who can rattle off the varied treatments for Crohn’s, is becoming accustomed to having the chronic disease. œIt’s annoying, but I can’t change it. jweidner@therecord.com |
| 34336. Hoi ik heb colitus ulserosa ok moet dinsdag mijn remicade hebben maar nu heb ik hoge koorts heb al contact met mdl arts beld mij terug maar kan het dan wel doorgaan ontstekings waarde 56 voel mij kloten. |
| 36058. Wie heeft er baat bij het gebruik van remicade? Humira werkt bij mij niet en nu willen ze hier naar overstappen. |
| 40395. Hallo Allemaal, Ben nieuwsgierig naar mensen met Crohn die ook Remicade krijgen. Bij mij schommelt mijn bloeddruk tijdens het inlopen van het infuus nogal, maar is vooral aan de hoge kant (153/110). Zijn er meer mensen die dit ervaren? Het is niet schrikbarend hoog en zelf merk ik ook niets van maar ben gewoon nieuwsgierig. Hoor het wel. Gr. Rudy FnSDhight pressure |
| 40424. Hallo allemaal, Ik heb even een vraag aan de mensen die ervaring hebben met Remicade. Ik heb nu 10 jaar Crohn en sinds een jaar krijg ik Remicade toegediend omdat geen enkel medicijn goed aanslaat. Nu slaat de Remicade ook niet aan zoals mijn arts had gehoopt. Wat is jullie ervaring met Remicade dat niet aanslaat en welk traject zijn jullie erna ingegaan?FnegSDn |
| 44178. Hoe veel weken mag er tussen de remicade "shots"zitten voordat je weer het opstart schema krijgt? |
| 45607. "Ik ga op reis naar Australiƒ« en gebruik Remicade. Dat moet toch eenvoudig te regelen zijn?" Helaas, het bleek anders. Lees de blog van Laurie: http://www.crohn-colitis.nl/crohn/blogs2 |
| 47907. Hallo ik heb een vraag zijn er mensen hier die aan de Remicade zijn en als bij verschijnsel verstopte neusholtes (verkouden) en een grieperig gevoel hebben na de behandeling, zou het graag weten wat ik moet een beslissing nemen om door de bijverschijnselen met de Remicade te stoppen, maar het helpt mij heel goed voor de Crohn. grtjs EllenFpSDsindrome semi influenzale |
| 47924. Beste CCUVN, Ik zou graag eens willen weten hoe het precies zit met het eigen risico als je remicade of humira gebruikt. Sinds 2012 wordt dit betaald uit het ziekenhuisbudget en hoeven we hier dus ook geen eigen risico meer over te betalen? Ik heb voor 2012 en 2013 gewoon moeten betalen en de eerste rekeningen zijn vorige week binnengekomen. Alvast bedankt, Lizanne |
| 47957. Hoi mensen, Ik zou graag willen weten of er mensen zijn die Remicade gebruiken en zwanger zijn of willen worden. Of er geadviseerd is om te stoppen met Remicade of tot een bepaald moment van de zwangerschap blijven gebruiken. Wat jullie ervaringen zijn. Groetjes, Nadia |
| 48571. Imuran, Humira, Remicade, anti-tnf. Bepaalde medicatie maakt je huid nog kwetsbaarder voor de schadelijke gevolgen van de zon. Zie ook het filmpje - dear 16 year old me!FnSDskin lesions |
| 49133. ik ben lid en zit aan de remicade |
| 49144. Heeft iemand ervaring met remicade bij colitis? volgens de mdl arts hebben we alles geprobeerd. Als iemand andere tips heeft hoor ik ze ook graag. |
| 55685. Hi everyone, I would love to get your support on this. It's an issue that anyone taking a biologic may face in the near future. Inflectra, the biosimilar for Remicade will soon be available in Australia followed by other biosimilars. Would you be happy if your biologic was substituted with a 'biosimilar' without your consent or evidence that it was as safe or effective as the biologic you are on? CreakyJoints Australia is calling on the government to urgently clarify its intentions regarding biosimilars and to revise its expectation regarding safety and substitution. Please sign this letter which will be sent to the Australian Minister for Health, Susan Ley, addressing our concerns. http://bit.ly/1M713Vw |
| 62203. Hi!! I just wanted to share with you all that I completed my first marathon yesterday. I'm obviously totally thrilled to have done it,... But also supper happy that I didn't need to go to the toilet for the whole 4 1/2 hours of running !! Exercise has been great for me & my UC. I'm on remicade too but exercise has given me a much happier body & mind. |
| 66110. Has anyone broken out in a red rash all over their body from remicade or Lialda?FnSDskin rash |
| 66244. Hoping for some advice... My 11 year old was diagnosed in 2011 and started Remicade infusions in September. He has been dealing with a psoriasis type rash all over his body and head. Cortizone cream is not helping. Anyone dealt with this?FnSDskin rash, psoriasis |
| 71224. La Comisiƒ³n Europea ha autorizado Remicade (infliximab) en el tratamiento de la colitis ulcerosa activa grave en pacientes pediƒ¡tricos de 6 a 17 aƒ±os que han presentado una respuesta insuficiente al tratamiento convencional. NA NA |
| 72232. My beautiful four year old daughter has Crohns. I know clinical trials can take longer to make their way to children but I'm absolutely terrified to think what they'll suggest next. She is on Remicade infusions and flared at 4 weeks maintenance so we are back on the prednisone. It's so difficult and I am trying to normalize it as much as possible and make the infusion days, hospitalizations, blood draws as fun as possible. I wish so badly I could fix this. She's got an incredibly good attitude about it all and the biggest heart in the world. She is all that is right and well with the world in one, sick little body. I am so hopeful. I will do anything. I will go anywhere, see anyone. I will do absolutely anything to help her. Hoping it gets better until we find a cure and we can keep her away from surgery. |
| 78158. We have now reached the impressive heights of Hero number 44! Please welcome Latoya to the team. This is her story: Hi my name is Latoya Holmes-Ivey. I have had Crohn's Disease for 12yrs now. It has been destroying me and my family's life. My Crohn's Disease came on me out of nowhere when I moved to Indianapolis from New York. It took me by surprise and I ended up in the hospital having surgery because my intestines where shredded, just as if someone had grated them like carrots. I had to have a small bowel resection. I have had 20 surgeries so far and have 3 more coming up. Due to this invisible disease, I am unable to live life like I used to as a beautician. I am unable to go outside and be the outgoing person that I used to be, enjoying family fun and life in general. My life revolves around hospitals, emergency rooms, and my bedroom. Doctors labelled me as a "Catch 22" because I had had Tuberculosis as a child and had no immune system to fight back. They have put me on every available medication and my body has rejected every one. I am now on Remicade which was the last resort but it wasn't easy putting me on this. I had to take Isoniazid for 6 months to suppress the TB before they could try; it was a risk with my life but I had to try something. I was determined not to be defeated by some disease I knew nothing about. Through my faith in God and with my family's support I am still here to tell my story and help to raise awareness. Now that there is hope for all of us, I will dedicate myself to raising funds so that All of us can Win this Fight. I Love you All! keep your Faith in God because We Are About To Take Our Lives Back!!! |
| 81886. Today we share April's story. "Our daughter, Hannah, is 14 & now, on Remicade infusions every 8 weeks and 6MP daily. She was a very healthy, chunky baby drinking a lot of whole cow’s milk until age 3. Then she slowly fell from 100%, to a negative 7-8% in height & weight on the growth charts. She had no symptoms, but I just knew something was wrong! Doctors told me she was "just tiny" and so I took her to a Paediatric GI doctor. By the time we got the appointment, 3 months later, she had blood, mucous, diarrhoea and belly pain. She was hospitalized and immediately given an endoscopy & colonoscopy to see that yes, she did have Crohn’s. She was on prednisone, Pentasa & mercaptopurine (6mp) and has been drinking Boost Plus nutrition drinks for two yrs. She's now gained 28 poundsand grown 5" more to catch up with her classmates! Stress makes her flare and she's always got chronic sinusitis." IT'S TIME TO CURE CROHN'S! http://crohnsmapvaccine.com/ Donate at: https://www.justgiving.com/CrohnsMAPVaccine-MEN9150/ https://www.justgiving.com/teams/crohnsmapvaccineheroes #crohns #crohnsdisease #IBD #crohnie #crohnsvaccine #MAP #curecrohnsFpSDweight |
| 83674. The antibiotics Rifabutin, Biaxin and Zithromax have helped heal my Crohns disease several times. I learned about them from Alan Kennedy's Crohns page which talked about Professor Hermon-Taylor's research. The Doctors wanted to put a bag on me over ten years ago but I refused and am still okay without it thanks to the antibiotics. I've recently taken Remicade as well but without taking one of the aforementioned antibiotics with it, the remission doesn't last as long. |
| 83715. How long does it take for the FDA to approve it after its developed? I was on Remicade for 12 years and now it's not working anymore. Going to share this info with my GI doctor. Thank you! Fp e neg SDn |
| 93314. Texas court overturns $5 million Remicade judgment: |
| 103548. Nyt on sitte mun tauti siin tilassa, ettƒ¤ alkaa Remicade-hoidot...kokemuksia? Mitƒ¤ kannattaa ottaa huomioon? |
| 106003. Can anyone give me some advice please, I have crohns with perianal complication I'm on remicade infusions but I'm getting terrible pain in my left hip, could this be a side affect of the treatment ??? X FnSDpains |
| 110224. zna li netko smije li se farbati kosa uz metotreksat i remicade? |
| 116869. My dd(14yo)has Crohn's. 3 years ago diagnosed. Had fissures, a fistula, abscess, and ulcerations throughout. Private practice gi dr let us go after I challenged her treatment plan. Took 9 months to see a gi doc at the state run pediatric hospital. During that time we went organic, gf, df, nothing fried, or fake, probiotics, & vitamins. "The impossible" happened, She got better! Time passed and went to new dr. Her scope showed only inflammation in ileum!!! He praised me left and right. Said, "I wish half of my medicated patients were doing so well!". Next scope (year later) showed same results with an exception 1 tiny ulcer. Dd had strayed from diet slightly. Now he is pushing for remicade. I'm at a loss. Diet DOES heal!!! Now I'm faced with medicating my child who I healed from severe Crohn's with diet alone over an ulcer or face their consequences. Lots of money to be made in "healthcare" |
| 118459. Has anyone tried Tysabri? My Remicade just wore off and I'm being bumped up to this infusion. Hadn't heard of it prior to going to Mayo Clinic a few months ago. |
| 119766. I just received my lab results call from Mayo...the anti-body tests came back great and I am able to restart Remicade after two years (the only medicine that has ever worked)! |
| 121524. So glad to find this page, I have had Chrons for almost 20 years now. I am on a medication called Remicade and having it by IV every 6 weeks. I am having trouble with my Chrons right now and just had a colonoscopy done and the results are not the best news I just have to wait for the biopsys to come in. But thanks again for this page. FnegSDn |
| 122565. What dose of Remicade do you take and how often? 10 mg every 6 weeks has lost its effectiveness for me. Anyone have that @ 4 weeks? |
| 122658. Have you switched from Remicade to Humira? Our friend Melanie F. wants to know how long it took to see results. Thanks everyone! |
| 122685. Has anyone changed from Remicade to Humira? How long did it take to notice a difference? |
| 130498. Does anyone out there have information about breastfeeding while being treated with Remicade? My first infusion is next week and I would like to know if I need to wean my son early. |
| 137321. Me getting remicade ,I have been getting it for 4yrs and its not helping me at all but it was the last resort after all pills failed and I'm allergic to it but I have no choice til now! FnegSDallergic |
| 139933. Hi Everyone, My name is Eric Yunker, from Saint George, Utah in the United States. I was diagnosed with Crohn’s Disease in 1997 at the age of 15. This was after more than two years of illness. Since then I have been on almost every medication in the book, including Prednisone, Imuran, Asacol, Remicade, and Humira. In June of 2005 I underwent surgery to remove 18 inches of necrotic intestine. At the time of my surgery I was 117 pounds. Shortly after surgery I gained some weight for the first time in my life. Around 2007 I found out that I have secondary inflammation in my liver due to Crohn’s Disease. In 2010 I underwent a fistulectomy to remove a recurring fistula. Then in the Fall of 2013 I underwent another operation resulting in two strictureplasties and another resection of a few inches of intestine. I have a wonderful Wife, Maggie, who I will be celebrating 10 years of marriage with this year. And an amazing Daughter, Evangalene, who just turned 4. I love them both more than anything in the world and hope to be around for them for many years to come. This Vaccine is a very significant step in Crohn’s research. There are very few teams currently working on anything for Crohn’s that could be considered curative. This is a huge deal! I’ve followed the MAP theory for a long time, there is a lot of data to back it up. It’s time to test the Vaccine! Please, if you are able, visit my fundraising link below and donate to support this research. Even if you cannot afford to donate, share this post with your friends and family, we need all of the support we can get! |
| 140461. Hej! Tƒ¤nkte hƒ¶ra med er om ni har nƒ¥gon erfarenhet av medicinen Remicade? Har en 13 ƒ¥ring som har haft bekymmer med sin mage i 6 ƒ¥r och nu har han blivit sƒ¤mre ! |
| 144291. So someone has again mentioned remicade infusions to me for the crohns disease. I never tried it before because I was told the Humira shots given to myself in my stomach weekly were stronger and better than the remicade, and since the humira wasn't working for me it was normal to figure the remicade was a step down. I'm thinking of mentioning it to my doctor in hopes of getting better, whic these vitamins are supposed to be doing but they aren't. The only problem is that I would have to go in every 8 weeks and get infusions lasting from 2 to 3 hours....and I have a 3 yr old. Plus with the surgery, doctors have said it may be hard to have another kid, and I don't want remicade to make that possibility worse. Does anybody have any advice or know anything or have experience with the remicade infusions?? And if it may cause any infertility issues?? Please let me know. I will also be speaking with doctor soon about it as well. Thank you |
| 145242. Any body on remicade and get bumps/hives that get hard and some bruise? They slowly started showing up And over the last 24hpurs they have got alot worse More pictures will be in the comments FnegSDskins |
| 148243. Has anyone experienced heightened anxiety after starting Remicade treatment? Our 9 year old is experiencing crippling anxiety since she started treatment in Dec.FnSDanxiety |
| 149455. Does anyone have any suggestions as to what can help with hair loss? Taking Remicade and noticing the loss. many Thanks FnSDhair loss |
| 152408. It was hospitalisation and a passion for knitting with goats’ hair that put Dr Judith Liipton on the path to anti-MAP therapy. She has now been in remission for 10 years. Read her story here and learn why she believes, as we do, that only crowd-sourcing, the power of the people, has the potential to overcome the self interest of the market place. "In 2004, I nearly died of septic shock as a result of penetrating abscesses in my colon, secondary to Crohn's Disease. I was hospitalized two times, the second time because I broke through conventional treatment with steroids, azathioprine, and Remicade (Infliximab). As luck would have it, I am a knitter and had kept fiber goats. I knew about Johne's Disease. So as I was recovering from the second hospitalization, I read that Crohn's could be considered a human form of infection with Mycobacterium Avium subspecies paratuberculosis (MAP), the same pathogen that causes Johne's Disease in almost all other mammals. I was able to connect with Prof. Thomas Borody, of Australia, and subsequently convince my primary care doctor in Seattle to try Prof. Borody's treatment plan for Crohn's: not anti-inflammatory drugs, but medicines targeted against multi-drug resistant tuberculosis, including rifabutin, clarithromycin, and clofazimine. I took my first dose December 10, 2004. I am writing this nearly 10 years later, and have not had any symptoms of Crohn's Disease or colitis or any gastrointestinal disturbance in almost 10 years since starting anti-MAP antibiotic therapy. Dr. Borody, from Australia, is a close colleague of Prof. John Hermon-Taylor, from the United Kingdom. Together, they have pushed the boundaries of treating Crohn's Disease to a whole new dimension, for which the whole world should be grateful. I don't think I would be alive today were it not for these good doctors. I had the honour of meeting Prof. Hermon-Taylor at the American Association for Microbiology special meeting about Crohn's Disease and MAP in 2007, and I have followed his work ever since. Prof. Hermon-Taylor is working very diligently to create a vaccine against MAP. This is extremely important, because MAP has been found not only in animals used for food or milk, but also in drinking water, showers, and biofilms throughout nature. While I continue to believe that it is a crime to allow animals with Johne's Disease into the human food chain, I understand that there are other natural reservoirs for MAP. A vaccine that would immunize individuals who lack the proper natural immune forces to kill MAP would greatly benefit humankind. Probably around 4 million people worldwide now have Crohn's Disease, with increasing numbers in South America and Asia, populations that did not previously show huge numbers of inflammatory bowel disease patients. Unfortunately, the medical establishment, including physicians and the pharmaceutical industry, have a lot invested in the so called "autoimmune" theory of Crohn's Disease. They make billions of dollars treating Crohn's as though it is a war of the body against itself, rather than a war of a pathogen against a host. In addition, the meat and dairy industries have a lot to lose, if they were to identify MAP as a human pathogen. The numbers of animals infected with MAP in Europe, Canada, and the US make Mad Cow disease look trivial. Prof. Hermon-Taylor's work directly challenges Big Medicine, Big Pharma, and Big Food. So it is no wonder that he has to struggle with paltry funding, while fancy new drugs that support the status quo get the research dollars. Prof. Hermon-Taylor is a medical pioneer, a brave man, and a genius. Please help to support his work! Neither governments nor industry is going to get this work done! If you have Crohn's Disease, or you love someone with Crohn's Disease, this work affects you directly. It is a clear case where only crowd-sourcing, the power of the people, has the potential to overcome the self interest of the market place." If you would like to read more of Dr Lipton's story, please see https://www.psychologytoday.com/¦/is-there-cure-crohns-part¦ IT'S TIME TO CURE CROHN'S! http://crohnsmapvaccine.com/ https://www.justgiving.com/CrohnsMAPVaccine-MEN9150/ https://www.justgiving.com/teams/crohnsmapvaccineheroes #crohns #crohnsdisease #IBD #crohnie #crohnsvaccine #MAP #curecrohns |
| 154306. So sorry to hear you are back in the hospital, I have been having terrible pains couldn't wait for Tuesdays Remicade Infusion, only it was cancelled because the tech was sick, now I can't get back in until end of Dec. Going through a divorce has inflamed everything, my Crohn's, Lupus, SICCA, Scleroderma, I hurt all over, and lost 22 lbs since Sept. Hope you get to feeling better soon! Marie. FnSDpains |
| 154410. Hi! I've had Crohn's Disease for 29yrs now, with 3 resections....no ostomies. My case is chronic from mouth to anus. =/ I've got no ilium which requires monthly vitamin B12 shots...pills don't absorb. All the meds I've been on....nothing has worked. I JUST started the biogenics way to do w Remicade. I'm a month in after my 3rd infusion & I'm still in pain. My guts have exploded & I became septic when I was 15, went into shock, & landed my first surgery; 37 now. I'm one of those w 9 lives! Feel free to send a message! :) FnSDpains |
| 157539. Anonymous Question: "Hey ive been really sick with crohns disease since February they have put me on prednisone for 2 and a hald months as soon as that was done everything became worst then what it was .. they finally put me on remicade in may .. ive had 4 infusions im going for my 5th on the 13th i react to remicade so i am there for 5 and a half hours for every infusion. Now since i started remicade i had hair loss fevers, massive weight loss .i cant hold anything down i vomit alot or comes out the other way no energy what so ever ive had abscess removed just last week.. i also have lots and lots of kanker sores in my mouth my fam doctor thinks it might b related to the remicade.. i dont know.... is there any other medication people would recommend or just have any advice on what i should do when going through a rough patch thank you" FnegSD hair loss fevers, massive weight loss, vomit |
| 158447. My first operation when I was 21 when I perforated my bowel & had emergency surgery. No bag required. I am now 28 & I have been having issues with my crohns since Feb of this year...seemingly getting worse not better - have just finished my course of IV infliximabe (Remicade) to which it failed. So I am now booked in for surgery on the 20th of this month and surgeon thinks very high possibility of a bag. Just after some advice or what to expect with a bag - thanks. |
| 158831. I was diagnosed with Crohn's Disease 3 months ago. I am trying to learn all I can about this disease. As of July 2, I had my 2nd colonoscopy as still had large ulcers in my colon (left side). I am on Imuran; Remicade; Uceris (steroid), an antibiotic, prenatal vitamin. My question is how do you know when you are in remission? Will you be pain free? All of May and half of June, I was confined to a bed, I have gained some strength back in the past 6-7 weeks. I lost a ton of weight, and have only gained about 7lbs back. It seems to me that the pain in my left colon area is related to the ulcers that were found there. The medicine I am currently on, doesn't seem to be getting rid of the ulcers. I just had my 4th Remicade infusion on the 16th. The pain can be pretty challenging. Not near as bad as the pain I had with the prerianal abscess I had back in late May. So my question for all those that have been suffering with this disease, what does "remission" consist of? How will I know when I get there?FnSDpains loss weight |
| 158915. Heather's Question: "Ok I have a question I'm hoping someone could help me with.... I have had crohns disease for 15+ years... They have tried me on so many different medications the last one was humira well ended up having some really bad side effects from it so now they r talking about remicade.... But the side effects I heard about that one scare me frown emoticon but at this point I'm willing to try anything so I can get rid of my second colostomy.... So if anyone could help me out n let me know what would be best it would be very much appreciated.... Thank u" |
| 159138. Michelle's Question: "How long can you stay on Remicade? I have been on it for 5 years with great success, fearing the day when it either no longer works or I am told I should go off due to side effects (of which I have none at the moment)" |
| 159700. Tera's Question: "I started remicade one week ago and it eased up on any joint pain I was suffering .. but symptoms are returning and I'm not scheduled for another week... thinking dr. Should up my dose; anyone else have reccomandations?"FnegSDpains |
| 160011. Josh's Question: "Hi, I wanted to ask a question about Remicade and what to expect with this treatment. I was having issues in January of this year that sent me to the hospital. After my initial hospital visit I was directed to a colorectal doctor for hemorrhoids. upon examination it was found that I had several large abscesses in my rectum. I had surgery in February of this year to drain and get rid of the abscesses. After recovery I was directed to Digestive Disease Associates in my area. They did a colonoscopy and found inflammation throughout my lower GI tract and a very large ulcer on my colon. The endoscopy also showed inflammation to my esophagus. I was given Canasa, an anal suppository to deal with the ulcer on my colon which sent me to the hospital because of adverse side effects. I was then put on Budesonide 3 times a day to help with the ulcer and inflammation. My doctor did testing to see if I was able to begin Remicade and she said that this is the next step in my process. I just wanted to know what to expect with the Remicade and if this will finally be the medication to help me into remission. At this point I have lost my job and have very few days each week where I feel healthy enough to even get out of bed to do anything. Can anyone give me some advice on what to do myself to help releive symptoms and what to expect with the Remicade. My life has been turned upside down in the last 7 months and I could really use any words of advice/encouragement to help me." |
| 160174. Kristi's Question: "My 14 year old daughter has fistualizing crohn's disease. She is on Remicade. It is sort-of working but the fistula isn't closing. Has anyone ever tried Genesis Pure? A family member has recommended it. Would appreciate any feedback. Thanks." |
| 160436. I wanted to share some good news. My husband has a severe case of Crohn's that developed while he was in the military. In his first year of diagnosis, they put him on a bunch of steroids and antibotics. It failed. In his second year, the VA put him on. It was also ineffective. In his 3rd year, they put him on humira but the damage was done remicade and he needed a bowel resection to remove the terminal ileum. After the surgery, we tried for him to be off meds completely and control with diet alone. Unfortunately, 6 months later, it was discovered in his colonoscopy that the Crohn's was still very active and causing damage again. 3 months later, he went on a combo of 6mp and humira. Although he's had some severe reactions to the 6mp, his colonscopy/endoscopy yesterday showed that he's finally now in remission! He continues to struggle w/ side effects from 6mp but we are so happy that the docs said his insides look good :)FpSDallergic |
| 160735. Anonymous Question: "Hello :-) could you please ask if anyone on remicade took live vaccines? Or any other vaccines? My doctor wants me to take the flu vaccine and I'm hesitant about it. Thank you!" |
| 162662. Anonymous Question: "Anonymous question: I was diagnosed with Crohn's in 1994 with a small bowel resection in 1995. Mild to moderate flares began again after 2001. I've was given Pentasa for maintenance with no other medications. Two years ago I was started on 5mg of Remicade for skin sarcoidosis and my inability to eat anything without having to use the bathroom. The remicade has only slowed the frequent bathroom trip but I still live in fear of going out and needing to go. Last year I was started on cholestyramine butit's s not consistant. I either can't go or go all the time. Does anyone else experience this with no active chrons? What medications are helping? What do you do? Help I'm missing my quality of live."FnSDcostipation |
| 164666. Anonymous Question: "I was diagnosed with Crohn's disorder a couple of months ago and right away started the treatment with Imuran and Remicade. It was out of the question to get pregnant during my treatment as I was in a flare, but mother nature had entirely something else in mind... so I conceived right after Imuran was administrated. Is absolutely wonderful to know I am pregnant but I am also afraid that Imuran might have affected my baby during conception. Right after starting the treatment I entered in remission and blood results are getting better and better, so most probably this is the reason for my pregnancy. My gastroenterologist tells me that there is a history with pregnant women which conceived during Imuran administration and all went well, but my GYN advises me to interrupt the pregnancy in max. 2 weeks as this drug is listed to D category with high risks for baby malformations, premature delivery, baby low weight. I am from Romania and this disease is very little or not at all known, so there is not much room for researching. So my very hopes go with my gastroenterologist which reassured me that there are no greater risks to conceive during Imuran administration than a healthy person... that in the international registries where spontaneous pregnancies under Imuran administration are stated, there has never been reported the risk category of the drug. As soon as I found out about my pregnancy the gastroenterologist stopped Imuran and told me to continue only with Remicade, and that there Is no reason to think about abortion. And my question goes to all of you who did conceive under Imuran administration, please tell me if your baby developed normally during pregnancy and after delivery were there any problems? I am really scared about this drug and don't know if it has affected my baby irremediably. My husband and me really want to keep the baby, but is this the right choice? Please, if you can reply don't hesitate... I just want to know your opinion." |
| 165599. Miranda's Question: "Anyone try Entyvio for crohns? I was on Remicade, Humira, and Cimzia they all worked for a little while then I guess my body built up antibodies to the drugs. Apparently Entyvio is newer, something has to give" |
| 165974. Chemotherapy for Crohn's: Methotrexate, Remicade, & 6-MP - http://bit.ly/1hShwyk |
| 166237. Anonymous Question: "My Crohn's is currently active and severe. My doctor is switching me to Entyvio to see if it gets me into remission. Remicade, Humira, Simponi and Cimzia have done nothing to help my condition in the past. Does anyone take this or have taken it? What can I expect? Side effects? Thank you!" |
| 168539. Ashley's Question: "HI everyone! My name is Ashley and I was just recently diagnosed with Crohn's Disease in February. It's definitely been a whirlwind! I am so thrilled I came across this page. I have a question! I discovered that I had Crohn's disease when my wound was not healing after I had a Fistulotomy back in September of 2014. I had a colonoscopy and MRI done which revealed inflammation- then the diagnosis came. Once I started on Prednisone, Remicade, and 6MP, my wound started to heal. However, I am still not completely healed (I still have a small wound that doesn't seem to want to close), but am still on Remicade and 6MP. So here's my question: Has anyone ever heard of Protandim? If so, what have they heard about it relating to Crohn's? And is it safe to take while I am on Remicade and 6MP? I have heard multiple stories, but I have not heard anything from anyone who is on other medications at the same time they are taking Protandim. Your insight would be extremely helpful! Thank you so much!" |
| 169895. Daniel's Question: "Hi I'v had crohns for the last 6 years and I 'm on remicade infusions every 2 months my question is there any long term effect/thank you" |
| 171563. Devastating ; I came down with symptoms of roumatory arthritis came on all at once. After fecal and blood work it is apparent the humira has failed me my inflamation measures double from when I started my treatment a year ago. Still want to have another child so methotrexate is out of the question but I hear remicade is safe ; I just wonder if the humira failed me will the remicade fail me too? Any feedback anyone ???FnegSDartritis |
| 172238. Which has been your first experience by REMICADE treatment |
| 172279. Oralee's Question: "Ok, my son is 10 will be 11 next month he had his fist round of remicade on the 21st exactly one week later he broke out in an aweful case of hives. Has anyone else had this happen? He wants to try remicade again and see if he has no issues. I am kinda nervous about letting him try one more time but we have already seem tremendous help with this medicine. I just wasn't sure if the side effect could be a one time thing because his body isn't used to it and has been inflammed for so long without our knowledge or what." FnegSDallergia |
| 172968. Karla's Question: "The doctor wants to put her on Remicade, we would like to know if this treatment is better than corticosteroids? She is 13 years old." |
| 174168. Anonymous Question: "I have had Crohn's disease for 11 years I was diagnosed when I was 9 years old. My disease started in the last 3in of my ileum (aka small intestine) over the years it has progressed to 10 or more inches of my small intestine. I am currently on Cimzia and Azathioprine. I have failed Remicade and Humira. My current flair (now going on 3 years) has caused me to throw up when food gets to my last 3in of my ileum. Has anyone ever gotten surgery on this part of the intestine and if so how did you convince your surgeon/gastroenterologist that it was the right thing to do?" |
| 174942. Anonymous Question: "has anyone with crohns and experienced severe might back pain right at the spin? It's not a pulled muscle and it gets worse with eating. I've also been on remicade for just over a year and back pain started about 6 months ago" FnSDpains |
| 175221. Question; our granddaughter was diagnosed with Crohns. The doctor wants to put her on Remicade, we would like to know if this treatment is better than corticosteroids? She is 13 years old. |
| 175315. Is anyone else taking nortriptyline for crohns? Doc added it to the immuran and remicade. |
| 175380. The pain is real. This week I started remicade. The infusion was not so bad but I really didn't know that I had arthritis. The pain was real for ten years everyone said that I could not be in so much pain. The back pain was real. I cried to find people just like me. In pain every day. I took one pill for the pain and it was gone in minutes. Thank you for telling me your stories. FpSDpains |
| 175959. My 11 year old daughter might be starting Remicade. Anyone have any advise? |
| 175968. Help!!!! My husband was told he has 2 fistulas, one to the bladder & 1 to the colon, he needs to have them surgically repaired, the general surgeon we originally saw in hospital that ordered drain for abscess etc told us to see another surgeon, colorectal, for 2nd opinion. (He never said he couldn't or wouldn't do surgery on him) just that it was a complex surgery. Are GI Dr got us an appt w a colorectal surgeon he felt was very good, we see him next Tues, but we spoke to GI Dr again today, & now he said he discussed my husband's case with 2 local general surgeons, and they're willing to take on the case..... I'm very confused on top of nervous and scared, my question is has anyone had intestinal fistulas that needed surgical repair, what type of surgeon is better in that field, & would you go with a local community hospital or a University hospital, like would you feel bigger hospital might offer newer technology, that might make surgery less complex than your regularly community hospital? Please any input would be greatly appreciated. He was diagnosed 15yrs ago, had a resection 13yrs ago to remove a stricture, about 6inches, went 11yrs with no flare ups, and about 7 of those years not really complying with meds, felt good so didn't take & got careless with diet. Had flare up last November 2013, with abdominal abscess, treated only w antibiotics, inflammation affecting kidney ureter, tried Humira a few doses can't say if it helped or not, than went on Remicade for 7 months, felt great gained over 30 lbs developed pulling sensation in groin inner thigh area, ct scan showed pelvic abscess, drain put in, when they rechecked & did a dye injection saw 2 fistulas that did not show on original ct scan. Currently on Pentasa, Imuran, Flagyl, vitamins & iron supplement. FnegSDallergic |
| 176007. I have a question. My eleven year old daughter was diagnosed with crohn's 2 years ago. Her doctor suggested remicade infusion. Do you have any advise, pro or cons you can share. Thanks! |
| 176011. I have been battling Crohn disease for about 5years and for the last two I've been treated with remicade it has been amazing I eat a lot better...No.flare us in two years No pain no vomiting n symptoms of Crohn disease but I do need away to get my energy levels up keep my blood pressure down and stressful situations such as work are hard to deal with I shake and blood pressure rises when I get upset/ stress but all in all I feel great and would recommend remicade to all my fellow Crohn disease friends |
| 176053. My son has been on Remicade for 3 years now and woke up complaining he only has vision in half his eye has anyone else experienced this on Remicade? No sure if it's connected or not? FpSDeyes vision in one eye |
| 176168. Has anybody had a successful pregnancy on Remicade and with a midwife not an OB? |
| 176296. I was recently diagnosed with fistualizing Crohn's after going in to the doctor with severe abdominal pain in my lower right stomach. I spent 2 days in the hospital to get the pain under control and have been on prednisone for 7 weeks and will be starting Remicade soon. My question is this-the only symptoms of a flare up have been the soreness in my side, where the doctor said the colon is inflamed. I've never had any of the other symptoms that typically go along with flare ups. Has anyone else had anything like this? It's hard to relate to reading discussion boards online because I don't have the same symptoms as a lot of Crohns patients. Any advice or to hear from anyone else that has a story similar to mine would be great to hear! |
| 176417. I have had Crohn's for over 30 years now and have been on Remicade and Humira, which I was allergic to both. Now my doctor wants to try Cimzia. Has anyone had any luck with this drug? I am curious because my doctor is having trouble getting approval thru my medical insurance and says I will have to pay like $1500. Per injection which is not happening. I am on permanent disability for my Crohn's and cannot afford that. If my Medicare approves it, just curious if it worked for anyone. Thanks, Mike . FnSDallergic |
| 176510. Hey guys, quick question....I've been on remicade since Oct 2012 and it's worked fine, my last infusion - I had an allergic reaction so the medicine didn't take. My Dr is switching me to Cimzia, anything I should be aware of with this medicine? Side effects? How long does it take to kick in? Thanks in advance! FpSDallergic |
| 176514. 36 year old diagnosed with Crohn's in 2008, they are starting me on remicade infusions, any advice, things to look out for? |
| 176593. Hi I have had crowns for 12yrs now and have had many highs and lows since been on remicade I have as far as my crowns has been great but I suffer so bad of joint pain I can't handle it have tried many pain meds but a lot make me sick the only one that don't is end one but Shirley there other drugs to help me can anyone help or had this them self ???? FpSDpains |
| 177009. Has anyone on Remicade decided to stop during pregnancy and then try to go back on after having the baby? With my first child, I had infusions all throughout the pregnancy. With this pregnancy, it pretty much has had me in full remission from the beginning. I was thinking about trying Humira once I have the baby if things go south. Anyone with any input? |
| 177048. Anyone do remicade infusions at home? If so does someone come and hook it up for you? Do you have a port? Does it cost more to do it at home? |
| 177089. Hey Everyone, it has been a long time....question. I switched from Remicade to Humiria 3 months ago. Is anyone fighting exhaustion, just drop dead exhaustion? |
| 177301. I need help- I'm starting remicade after failed humira,6MP, and multiple other things. I just found out my crohns has now spread to my small intestine. I'd like to hear everyone's story about remicade...good, bad and ugly please! I'm exhausted with treatments, and scared of what's to come with the treatments of remicade. Any advice/story is greatly appreciated |
| 177350. Well....I have been doing really good. No signs of any flare ups and living life to the fullest. However, I have noticed this month that my knuckles and knees (especially my right one) hurt. My knee feels like its going to explode at times. My remicade treatment isn't until the 27th....is this common? Is it something to worry about? FnSDpains |
| 177463. Well friends, the gastroenterologist wants to take me off the Imuran and put me on Humira or Remicade. Still flaring. I will continue to press on, and continue to trust God. |
| 177662. Well back home from having a sigmoidoscopy today. Had it done with no sedation, so I felt everything and seen everything. At any rate, doctor wanted to see why I was bleeding so heavily. Every time I come off the steroids, it starts up again. The doctors believe my body is steroid dependent. They have increased my dosage of Imuran, and put me back on the hydrocort and rowasa enemas. Should this not work, the next option is remicade. |
| 179322. I had my second Remicade infusion. Both infusions I get absolutely wiped out and sleep the whole day. Is this common? (I just don't want to hear any other negative things about Remicade because I have no choice but to take it and I don't want to get freaked out) thank you! FnSDtired |
| 179843. Hi everyone. I have some VERY IMPORTANT INFO to share. Some of you may be aware of this already but if you aren't you should be. NO ONE ever told me this and I didn't ever think of it on my own but if you are using Humira or any other TNF blocker like Remicade or Cimzia etc....be sure to let your Veterinarian know.If your pets get any vaccinations they have to get the killed vaccines and not the live ones or you could get sick! This is HUGE and I can't believe doctors don't tell us this kind of stuff!!! |
| 180879. So this colitis decided to spread. My entire colon is not infected with it. The doctors exact words after my colonoscopy, "The colitis is back, and it is back with a vengeance." So, I was on Asacol, now on Lialda, along with prednisone. They are talking about Imuran or Remicade. If you are on Imuran or Remicade, how has it been for you? Reading the side effects they are nasty. |
| 180923. Had my first Remicade treatment today since my resection surgery on April 19th. So far I'm feeling fine. :) Hope everyone out there is doing well. Good luck to all. |
| 181072. A few of my friends have recently had Shingles (usually middle age people who had the chicken pox as kids get it,and it is supposed to be horribley painful) so I went to my Dr. to ask about the vaccine that is now available. I was refered to an infectious disease Dr. who made me wait 2 hours then looked at my chart, and said "I will be right back" as he walked across the hall to a commuter, clicked on it and came back saying "Sorry you take Imuran and Remicade, they are live biologicals and so is the vaccine and the worse news is that you are immunosupressed so at a much higher rish for Shingles.", Turned around and left! No bedside manner at all. So much for trying to be proactive! |
| 181439. I am 47. I have had CD since 1996. Used Remicade from 2002-2010 and had a WONDERFUL remission and quit Remicade. Had my gall bladder removed a year ago and everything got really bad after that. Had a miserable flare last summer and started CIMZIA. It helped for a while then I got sick again in March. I have been flaring for 6 weeks. Very badly! I am in the BR 15 times a day. Sleeping maybe 2-3 hours at a time during the nite if I am lucky. The BMs are very painful and there is a lot of blood in my BMs. I have a low fever. I went for stool samples for C Diff and parasites and bacterial infections. All came back negative. I am absolutely miserable and need some medical care. My Doctor is at Cleveland Clinic. He is 80 miles from my home. My local hospitals have inferior care they will just pump me full of prednisone and send me home. My doctor wants me to have a colonoscopy but cant get me in for 6 weeks to do one ARGH! Should I just make the trip to the Cleveland Clinic ER and hope to get admitted and get the care I need before I am too sick to function? I hate to make that trip only to be sent home. I am not getting any treatment for this flare. I can't go on like this. Any suggestions will be greatly appreciated. FpSDpains |
| 181734. Having a pretty shitty day today :( my remicade is wearing off, all my muscles ache, some of my joints hurt, I feel so tired and worn out.... I feel like i have ran 100 miles FnSDpains aches |
| 182338. Not sure how this works but I figured I'd give it a try. I'm currently on Remicade and have been for 3 &1/2 years. Diagnosed for 6 years. Every now and then (even before starting this med) I feel like I have extremely sore/sensitive skin. It's always on the backs on my arms and through my trunk (back, stomach, and esp breasts). Curious about the cause. Hugs are the worst, which is awful because sometimes that's just what we need. FnSDpains aches |
| 183089. It's so nice to find pages for Crohns patients and families. I have a 16 year old son and he was diagnosed with Crohns on January 22, 2009. He has been through more than any child should ever have to deal with. It's not easy to find people to talk to that understand what we deal with on a daily bases. Gage has been on Remicade and failed. He had resectioning surgery on March 19, 2010. He takes humira now, but he still has abdominal pain every day. I wish I could just take this all away for him. We recently found out that our 9 year old son may have Crohns as well. I've adjusted to dealing with one child having crohns, but two? I may lose my mind. We need a cure and I wish I could take all of this away for all who suffer! FnegSDpains |
| 183943. Dodged a bullet this week. On Saturday began vomiting and diarrhea, then those horrible cramps that have become so familiar when I have an intestinal blockage. I have a ton of adhesions from surgeries and fistulas, but by Suday night I was able to drink small sips and everything stayed down. Monday I had an existing appointment with my GI, whos-sent me for tests and an IV but allowed me to go home because somewhere in there, they heard a tiny gurgle. No NG tube! He released me and by that night, everything had resolved itself. The next day I went for my Remicade infusion and waiting for me there was a prescription for 6 weeks of prednisone, I also take immurane as a immune suppressant. I have never had the 3 combinations before and now everything tastes like I have a penny in my mouth. I am so bummed about the prednisone, but at least no hospital stay. Prednisone makes my hair curl, along with other side affects anyone else ever get that? |
| 184387. going back on entecort and in a few months going on remicade or humira. can anyone fill me in on what i need to know about remicade or humira and what side affects usually occur. I am a bit scared about this. |
| 185176. I know that depression goes along with Crohn's but does anyone out there who is on Remicade find that after a few weeks (for me its about 6 weeks, I'm on an 8 week infusion schedule) it gets worse? I don't know if its just because my symptoms are starting to return or if its a side effect of the medication but I just get so depressed nothing makes me happy. I feel like I have the weight of the world on my shoulders. I'm not suicidal or anything just unhappy. I hate that feeling. Does anyone have any suggestions. Some people tell me to ask my Dr for antidepressants but I really don't want to take meds. I have thought about Yoga I have heard that helps. FnSDdepression |
| 185664. Guys, need HELP ON THE RECENT POSTS WALL! Please... Wyatt has a Bump on his head after Cimzia Injection (See meagans Post) Kristen would like to know about Humira and Leg Cramps, and Nicole is weighing Surgery OR Remicade and needs to hear about our experiences to help her chose! PLEASE CHECK THE RECENT POST WALL TO HELP OUR PAGE MEMBERS! THANKS and i hope all are hanging in there ok! ~Sara |
| 187528. There some questions on the wall if anyone has a minute.. Rashes, Flu Shots, and Remicade/shortness of breath + more. THANKS EVERYONE, and happy thanksgiving to our Canadian Members! Sara FnSDrashes |
| 187632. Another Question for a page member who is needing support and advice. Help if you can! Hope all are feeling okay today. <3 ~Sara I have a question to ask everyone. I was diagnosed with Crohn's when i was 13, im 17 now, I just had a baby and my crohn's had been pretty good until my idiot obgyn told me to get off the pills and that totally messed everything up. (later i switched to a different doctor and she told me i should have been on them all along) Ive only taken azathioprine, asacol and prednisone, im on azathioprine right now, basically its not working at all. Im having REALLY bad pains like, it hurts more than labor did. They just did an MRI on me, I dont know what the results are, but at this point i would have 3 choices, remicade weekly, prednisone again, or surgery, which you know... i REALLY DONT WANT. But its really bad... what should i do? Remicade is really bad, but the steroids arent working as well as they used to. should i try the steroids for a while or try remicade? someone help please!!! |
| 189816. Hey all, thanks for being such amazing page members and helpers. The wall is full of questions today.. Stuff i cannot answer, Blood transfusions, Remicade/Humira and scar tissue surgery... PLEASE HELP WHERE YOU CAN. Hope this finds you feeling okay everyone!!! Sara |
| 193265. \*\*Crohnnie friends, I have a personal request for some support answers: I have a friend who is young, and on Remicade. It has been effective for her for some time. Recently, she has become quite lethargic and she is losing weight. Anyone have anything to suggest? I don't think it's a Remicade side effect, is it (losing weight)? Grateful for your help ~ b FpSDlosing weight |
| 194215. Evening/Morning to all around the world! Thinking about you all out there who are suffering, or watching someone who is suffering. Positive thoughts, strength, and healing going your way! A few new posts on the wall of people needing support and questions answered! Perhaps you can help--we have question regarding fissures and surgery to remove... Remicade and baby questions, Colonoscopies and triggering flare ups, UC patient- who is now concerned about Crohns--but AFTER having the whole surgery. +MORE-- HELP HELP HELP if you can!! Thanks everyone, i really appreciate it. I wish i had all the answers, but we need the help of all of you! Thank you SO much for being a part of such an amazing group, of amazing fighters. I Hope this finds you fighting HARD! ~Sara |
| 198927. \*\* Re-Posting this in case anyone can help out ... It may have moved down the board and got missed yesterday. Can anyone help our friend Stuart with this question : "Hi im fairly new to this page and am not one to usually speak,i have crohns and cutaneous crohns on my buttocks which gets very sore,itchy and can leak which is kinda smelly when it flares up independently of my bowel crohns,im on aza and remicade but soon im coming off that and going on humira and increase my aza. I was wondering if anyone else has this problem as i cant seem to find much info on it. Ive been diagnosed 1 and half yrs ago but have only just got a name for my skin problem and the doc just says its pretty rare,any help would be appreciated :-) " Like ‚• ‚• Yesterday at 03:07 FnSDskins |
| 199474. Remicade is the world's best-selling medicine ($9 billion!), but it goes off patent in 2018... here are some bio-similars (~generics) already available in other countries, or soon to be available in the USA.... |
| 199603. Does broccoli taste better when you're taking Remicade? Apparently TNF makes food taste more bitter, and since Remicade is anti-TNF... |
| 200045. While I see the value of sharing positivity and success stories, I feel it contributes to alienation of Crohns suffers such as my teen who has had three surgeries in three years including an ostomy. Remicade which is a powow, bonding drug for some, actually built up volatile antibodies in our daughter bringing her out of remission and lead to six week long hospitalization and an attempt to get her back into remission with another drug. She finds the process painful, sad and discouraging and when we seek out sources and groups, we only find success stories, those who just need a diet change and stories of triumph to which we have not been able to relate. We do not have a support system of cheer leaders and have even had a depleted IBD staff who could not cover all of their patients and have had to change hospitals twice and specialists three times. This is a miserable disease. FnSDpains |
| 200355. My 12yr old son has crohns (diagnosed about 5 yrs ago), I found this site from the Crohns Advocate magazine. After trying several regimens to control the crohns, my son started remicade every 8 wks about a year ago. Its worked well, but now we need to go every 7 wks, he can't hold out that extra week. As a parent, my heart aches for my little guy... We just had a new blood test to see if his body is forming anti-bodies to the remicade, waiting for the results for the dr... FpSDaches |
| 200815. It is very exciting to have found you. My daughter has Crohn's and she has been avoiding Remicade for years by doing 6 weeks of exclusive enteral nutrition orally. She is now finishing her second time around with excellent results once more. I found this treatment through the Miami Dade Public Library, and when I asked the GI why she had not suggested she said there were not enough clinical studies in the US about it (although it is the first line of treatment in the pediatric IBD protocols of such countries as Great Britain and japan!) Even the brazilian dietitian in the group was surprised more patients didn't not try this treatment. Since then I have tried to let as many people know as I can, and even got the GI to let me coach parents on how to do this treatment orally so children will have a good energy level through the day and keep up their regular activities. I also found out that this treatment is excellent for adults. If only I had known before my daughter would have avoided prednisone and 6MP. I think that what you and your team are doing is fantastic, and hope it is working soon. I have already signed up! |
| 201655. Stor fransk hospitalsgruppe vƒ¦lger biosimilƒ¦rt lƒ¦gemiddel - 45 % rabat Det biologiske lƒ¦gemiddel Remicade, har mistet sin patentbeskyttelse, og nye versioner af lƒ¦gemidlet er dukket op. De sƒ¥kaldte biosimilƒ¦re lƒ¦gemidler, der har samme virkningsstof som originallƒ¦gemidlet - dvs. "Infliximab". Den franske hospitalsgruppe, der servicerer en fjerdedel af den franske befolkning, vil fremover behandle autoimmune sygdomme (som fx Crohns sygdom) med den billigere "Infliximab"-version, og ikke det velkendte brand Remicade (der i Europa har en ƒ¥rlig omsƒ¦tning pƒ¥ cirka 15 mia. kr.). Priserne pƒ¥ biosimilƒ¦re lƒ¦gemidler varierer, og er afgjort med til at fremme udbredelsen af dem. Norge har fx forhandlet sig frem til en rabat pƒ¥ 69 %. Flere andre biologiske lƒ¦gemidler mister snart deres patentbeskyttelse, sƒ¥ der vil dukke endnu flere biosimilƒ¦re lƒ¦gemidler op pƒ¥ markedet, og helt nye problemstillinger. Du kan lƒ¦se meget mere om biosimilƒ¦re lƒ¦gemidler i det kommende CCF Magasinet (CCF's medlemsblad), og ikke mindst lƒ¦se om CCF's holdning til brugen af dem. Lƒ¦s mere om den franske hospitalsgruppe (engelsk): NAhttp://www.reuters.com/article/2015/07/07/us-france- |
| 215828. Nyt prƒ¦parat mod tarmsygdomme viser god effekt Fase 3-studier viser, at nyt antistof kan begrƒ¦nse sygdomssymptomer hos patienter med Colitis ulcerosa og Crohns sygdom. Bemƒ¦rk: D. 22. august skrev vi (Colitis-Crohn Foreningen) om nyheden med titlen "Nyt effektivt middel mod IBD...", Den danske version i dag, er fra Dagens Medicin: Det eksperimentelle prƒ¦parat vedolizumab viser lovende effekt som behandling mod de to kroniske inflammatoriske tarmsygdomme Colitis ulcerosa og Crohns sygdom. Det viser resultater i to kliniske fase 2 studier, der er offentliggjort i tidsskriftet New England Journal of Medicine. Vedolizumab formƒ¥ede at mindske symptomer hos patienter, der tidligere havde fejlet behandling med nuvƒ¦rende standardbehandlinger. De to inflammatoriske tarmsygdomme opstƒ¥r, nƒ¥r immunsystemet indleder et angreb mod slimcellerne i fordƒ¸jelsessystemet med kronisk betƒ¦ndelse, diarre og blƒ¸dninger til fƒ¸lge. Vedolizumab, der er udviklet af lƒ¦gemiddelfirmaet Takeda, virker ved at forstyrre transport over tarmvƒ¦ggen af de bestemte immunceller, der forvolder inflammationen. Vedolizumabs virkningsmekanisme forventes dermed at kunne begrƒ¦nse de bivirkninger, der normalt er forbundet med de andre prƒ¦parater mod tarmsygdomme, der undertrykker immunsystemet. De to studier involverede mere end 2.000 patienter med enten colitis eller Crohns sygdom, der ikke responderede tilstrƒ¦kkeligt pƒ¥ de immunundertrykkende standardbehandlinger som kortikosteroider, Imuran og Purinethol. Halvdelen af patienterne havde ogsƒ¥ prƒ¸vet de nye biologiske lƒ¦gemidler mod sygdommene som Remicade, Humira og Cimzia. I det ene studie modtog knap 900 colitis patienter to infusioner med to ugers mellemrum af enten vedolizumab eller placebo. Efter seks uger oplevede 47 pct. af patienterne pƒ¥ vedolizumab et klinisk relevant respons med fƒ¦rre symptomer, og efter et ƒ¥r var sygdommen hos 42-45 pct. af patienterne pƒ¥ vedolizumab pƒ¥ retrƒ¦te, mens det kun gjaldt for 16 pct. af patienterne pƒ¥ placebo. I sammenligningsstudiet af 1.100 patienter med Crohns sygdom viste de tilsvarende data, at 31 pct. af vedolizumab-patienter responderede pƒ¥ prƒ¦paratet efter seks uger, mens sygdommen efter et ƒ¥r var pƒ¥ retrƒ¦te hos kun 36-39 pct. sammenholdt med 22 pct. af placebopatienterne. Det er endnu uklart, hvorfor vedolizumab sƒ¥ ud til at virke bedre for patienter med colitis end Crohns sygdom, men en forklaring kunne vƒ¦re, at Crohn’s i modsƒ¦tning til colitis ikke er begrƒ¦nset til tarmen, men kan ramme alle dele af fordƒ¸jelsessystemet. Samtidig er Crohns sygdom en mere omfattende sygdom, hvor patienterne sandsynligvis behƒ¸ver mere end seks uger for at opleve et respons. Crohn’s patienterne havde ogsƒ¥ flere bivirkninger ved vedolizumab, hvor colitispatienterne kun oplevede fƒ¥ milde bivirkninger pƒ¥ niveau med placebopatienterne. Forskerne forventer, at vedolizumabs gavnlige effekt mod colitis gƒ¸r, at prƒ¦paratet sandsynligvis bliver godkendt mod denne lidelse fƒ¸rst. New England Journal of Medicine 2013; 369: 699“710: Vedolizumab as Induction and Maintenance Therapy for Ulcerative Colitis New England Journal of Medicine 2013; 369: 711“721: Vedolizumab as Induction and Maintenance Therapy for Crohn’s Disease NA |
| 216377. Gostaria de esclarecer uma duvida (qual ƒ© a relaƒ§ƒ£o de Remicade e Infliximabe?) ambos sƒ£o o mesmo? Se houver alguem que intenda do assunto por favor preciso muito saber dissoNANA |
| 216677. Boa notƒ­cia!!! Atƒ© pouco tempo apenas o Remicade/Infliximabe era liberado para tratamento da retocolite ulcerativa no Brasil. Mas em outubro o Humira/Adalimumabe tambƒ©m foi liberado! Leia mais em: http://crohnecolite.com/humira-liberado-para-retocolite-ulcerativa NA NA |
| 218927. Pergunta de paciente: "Olƒ¡ boa noite, tenho a doenƒ§a de Crohn e vou comeƒ§ar um tratamento com o Infleximab ou (Remicade), os efeitos secundarios sƒ£o mais que muitos e estou um pouco apreensivo. Pretendia saber o vossa opiniƒ£o e se alguƒ©m ja fez este tipo de tratamento e quais os efeitos secundƒ¡rios mais frequentes. Obrigado Cumprimentos." Vocƒª estƒ¡ tomando infliximabe (Remicade)? Como tem sido sua experiƒªncia? Teve alguma complicaƒ§ƒ£oNA NA |
| 219311. Qual tratamento biolƒ³gico escolher - adalimumabe (Humira) ou infliximabe (Remicade). Trƒªs estudos mostram que nƒ£o hƒ¡ diferenƒ§a entre esses medicamentos no que diz respeito a eficƒ¡cia. http://www.crohnecolite.com.br/2014/06/infliximabe-ou-adalimumabe.html NA NA |
| 231997. Has anyone been on Remicade IV therapy that could tell me how they did with it? |
| 238901. So I have a question for all of you. I'm on Remicade, but thanks to a small flare, back on Prednisone. So many people say how it makes them nutty/energetic/superhuman, and here I am beyond exhausted, ready to fall asleep at ANY time! Does this happen to any of you? Any pointers on how to combat this extreme exhaution, short of gallons of caffienated drinks (which really just make things worse)? Thanks in advance. FpSDtired |
| 262517. need help please my son lives in san antonio and needs remicade treatments does anyone know of an assistance program to help pay for this |
| 262605. question, my son has had 3 infusions with remicade and devoped a large wart on his elbow... has anyone else had this happen? FnSDarthritis |
| 267096. I was supposed to start remicade and found I have a skin infection so its been delayed.Time off work and 1 hour driving. Frustrating. So glad I had a peaceful weekend thanks TCJF |
| 267643. I have started azathioprene and am scheduled for infusion therapy Remicade (infliximade) .Any input or dietary suggestions would be appreciated. Thanks |
| 275592. Hey peeps. Ive been battling Chrohns for 20years now. Have been on prendisolone for majority of that even after surgery. Ive been on Imuran for a few years now. Im feeling ok at the best of times but I think you just get use to the pain. The docs are reviewing me for REMICADE -(Infliximab). Id really appreciate any feedback from anyone regarding this medication. Its a bit of a worry being on it long term as the side effects sound awful. P.s this is my first ever attempt of online advice..big step for me. Sending lots of Healing vibes to all your bellies ;) alli |
| 275904. Hi Sarah, I had a gastroscopy and colonoscopy today and they found that I may have Crohns mainly in the stomach ( gastric's crohns) which is rare apparently. Please ask your followers if some of them have this form of disease? what kind of medical treatment /drug do they take? How do they manage their disease ? I have been diagnosed with Crohns in 2012 but at this stage they had not checked my stomach even though I told them I could not eat at all because of the burning sensations. Was on remicade, then Went off medication , was in remission, and now disease is coming back :-(. Fp e negSDn |
| 276630. One thing I wanted to mention to your folks on here that have been on or currently on Remicade...I noticed (10 years post Remi) that I started getting a lot of Basal Cel Skin Cancers (one was aggressive and needed 20 stitches down my face and MOH's surgery) Please, if you have been on Remicade, get a full body check at least twice a year--find a good and thorough dermatologist who understands the possible side affects of Remicade. Use Sun block, and hats, and don't mess around. I let the one on my face go for 1 year--because I blew it off--and it turned into a not so pleasant experience! Bell well and sun safe! FpSDskins |
| 276745. My doctor is switching me from cimzia to remicade. Any advice or things I should look out for? |
| 276757. We received this in our Tumblr inbox. She did ask this question to others, but I went ahead and answered it, since I have experienced taking Remicade. Please, if you can give any advice post it here! |
| 277041. I had my 3rd infusion of Remicade last Friday and it triggered intense fatigue, dried eyes and migraine, 48 hours after the infusion. Does anyone know this kind of side effects ? FnSDtired, dried eyes and migraine |
| 278361. Attempting remicade without pre med for the first time in 6 years... Too much to do today... Wish me luck! Lol |
| 278858. Has anybody here ever experienced sudden, uncontrollable weight gain and/or significant Edema on their legs without being on some type of steroid? I am only on Remicade right now, and over the last year I gained 20lbs and can't seem to get rid of any of it. I can't afford to keep buying larger clothes. I even saw a nutritionist and worked my butt off for 2-3 months on a strict diet and working out 3-4 times a week but I only lost 2-3lbs which may have been a fluke. I got tested for hypothyroid and am told all is in order there. Most diet type pills really upset my Crohn's and make my stomach ulcers act up. I am increasingly depressed and feeling hopeless. SOMEONE PLEASE HELP! Thanks everyone! Hope you have a wonderful day and that you're all feeling well. <3 FnSDweight gain, edema, |
| 279007. Can anyone tell me the pros & cons & the differences/similarities of Remicade & Humira? I'm in the medical field, but don't have personal experiences. Also, I REFUSE the flu shot bc I do NOT like injecting myself w anything foreign. I'm a patient of a chronic case of Crohns Disease for 28yrs w 2 surgeries. I have a 4in acute stricture. Can anyone help? |
| 279407. Has anyone tried Remicade Infusions? opinions please. I start tomorrow morning. |
| 279540. Hi guys , wonder if you can help. I,m sure I read in your feed somewhere about painful joints after having remicade infusions. Well I,'ve had 5 now and my knees are so painful at the moment, does anyone else have this happen FnSDpains |
| 279623. Need advice!?!? I've been on Remicade for a year. Well I had an ulcer n was in hospital 3 days and missed infusion. I can't see my gi till jan 16. I'm having below the knee edema. My ankles n foot are terrible. I've never a side effect this whole time. Pls need advice FnSDpains, Edema |
| 279983. I've just signed myself up to be a research dummy for 2 years too help all us crohnies on humira an remicade.. lets hope they can do it :) |
| 301361. Giuliani’s new drug, Mongersen, is unique from other biologic treatments for Crohn’s disease, such as Remicade and Humira, because it is a pill and the others are injections. |
| 303023. FYI: Remicade‚® Users Unite has set up an online petition at http://ccfc.delivr.com/1hinx that calls on Canada's provincial and territorial governments to combine their buying power and purchase Remicade‚® in bulk, believing it will result in a better price and increased affordability. They've also set up a facebook page:   http://delivr.com/1hith |
| 308580. Bonjour a tous , a toutes les personnes qui ont ƒ©tƒ© sous remicade, avez vous eu des soucis de tentinites, car j'ai eu du remicade pendants 7 ans, j'ai arrƒªter il y a 2 ans. Mais depuis 6 mois je souffre d'une tentinite au 2 poignets, alors je me demandais si il pouvais y avoir un rapport. Merci FpSDarthritis |
| 310131. cela je ne savais pas qu il existe le generique de Remicade   http://www.medscape.fr/voirarticle/3582477 |
| 310267. Bonjour tout le monde, voilƒ j'aurais une petite question dont j'arrive pas a trouver la rƒ©ponse, j'ai la maladie de crohn, je suis sous remicade et immurel depuis une an et je voudrais me faire plusieur piercing et je ne sais pas si c'est possible ou pas quelqu'un aurais dƒ©jƒ fait avec ses deux traitement ? |
| 310390. Bonjour tout le monde. Petite question. Grossesse et remicade sont ils compatibles? Sur le net des tƒ©moignages de femmes qui ont passƒ©s les 9 mois avec remicade ( et bƒ©bƒ© va trƒ¨s bien). Et d'autres qui disent qu'il ne faut surtout pas ƒªtre sous remicade durant la grossesse. |
| 310405. Bonjour, je voulais savoir si quelques'un d'entre vous avez de la tachycardie apres l'injection de remicade moi ca allait bien la et depuis 17h j'ai mes courbatures comme d'habitude mais aussi de la tachycardie ƒ l'heure qu'il est... Merci d'avance FpSDtachicardy |
| 311121. I recently switched from remicade treatments to Entyvio. I just received my 2nd dose of starter doses yesterday. I will have my feel good days and then today I wake up and my joints hurt so much it's hard to move. Anyone else experiencing these symptoms? What are you using to help? I've been taking Tylenol and IB profen but know I'm killing my liver :(. FpSDpains |
| 311414. Can anyone tell me, is it unsafe to get tattoos while your on methotrexate injections? I had one get infected after I had a remicade infusion (Which I had a crazy reaction to, so I only got one infusion) I had got a tattoo with a purple ribbon for crohn's and it got infected. Tried to get the purple touched up a year later, and my skin was too thin and he couldn't get it to hold color. I really need some tattoo therapy right about now, but am scared as I have been doing methotrexate inj's over 2 months now, and will have to for a long time, to keep my crohn's in remission. I appreciate all input! ;) FnegSDn |
| 313457. I have had Crohns disease for four years and have reacted badly to every medication they have tried. I just had to have emergency surgery for a hole in my bowel and am pretty scared. I am a single mom of three young children and my doctors have basically told me to have all my ducks in a row regarding there future. I was just taking Humira which was a fail and now my doctor wants to put me on Remicade. Does anyone have an opinion about this drug ? Has it help? Right now I am open to any suggestions as to what I can do to try and fight this as I need to be here for my kids-I can't let this beat me. Any input would be awesome. Thank you. Tyler. |
| 313607. Im starting my first remicade infusion friday? Anyone have any pointers? Currently im recovering from perirectal abscess that i had surgery on 8/6 courtesy of crohn's... |
| 313966. I was diagnosed with Crohn's at 16 years old and at 17 was started on Remicade. After about 7 years, my body started becoming immune and symptoms got worse and worse. I am married and my oldest daughter was four when I had my surgery 2 1/2 years ago. My entire large I testine was removed and I have a permanent colostomy. I have also been diagnosed with osteoarthritis. I met Dr. John Edwards and have been taking this nutrition supplement for about four months now. My enrgy levels have increased dramaticallyalong with my pain levels. This is all natural which I love. I was tired of one medication causing more health issues; I have more than enough to deal with as it is. This link is a presentation Dr. Edwards did to educate people about this amazing product. Please listen and I would be happy to give as much information as I can to anyone who would like more. Message me http://m.youtube.com/results?q=dr%20john%20edwards%20mangosteen&sm=1 Fp e neg SDarthritis, pains |
| 319399. Question for all of you. I am working on quitting sugar. I was hooked. Ginger ale was the only thing that helped with the nausea in the evening. I'm on remicade every 5 weeks. All I've done is stop the honey in my tea every morning, the ginger ale in the evening and cut out sweets. I'm following the advice of Sarah Wilson 's book "I Quit Sugar ". And it's been 4 weeks. My question is have any of you done something like this? And why am I so sick???? My diarrhea is out of control, I'm exhausted about half of the time, and the nausea is SO BAD. I'm ready to throw in the towel. But I thought I'd check here first. Thanks all. FpSDdiarrhea, nausea |
| 320801. My Dr. Switched me from Remicade to Entyvio and is now going to give me mercaptopurine (mp-6) as well. Anyone else on this treatment plan for UC? Any advice / info on the 6 mp? |
| 321342. This was an interesting read. The study fixated on Infliximab #Remicade only, but I do have to wonder if the results would be similar if not the same with pediatric patients taking Humira as well. Humira was recently cleared for pediatric use; Remicade has been the gold standard prior to. I don't know about any of you,, but I know I wish I had been diagnosed properly when I was younger and treated accordingly. I might have had a fighting chance to not have my growth stunted and not suffer from #shortgirlproblems! \*Jai\* |
| 324149. Ok I was wondering is there anyone eles who has been diagnosed with chrons in bowel and even after two years of remicade it moved to lungs and any where eles. I have been confirmed as a rare case and have already had part of a lung removed and worried what other organs it could effect. I am not responding to meds had first dose envito seemed to make me worse. Waiting to see ent because last visit I had inflammation in nose and have been battling nose bleeds and head aches |
| 324961. Any info on hair loss from remicade infusions? FnSDhair loss |
| 325375. Hi. I'm new to this page. Thanks for the invite! I have a 14 year old boy with Crohn's. He just started on Remicade. He also submitted his saliva to a IBD genetics study. We just got results back today and it is really fun to see the genetics. Have you all done this? www.23andme.com/ibd |
| 326103. Hey! I have a question. Does anyone have experience with a port? I had my remicade infusion this morning and it took 10 tries to get an IV started. I've always been a hard stick. They've had to use an ultrasound to find veins before. Are ports really convenient? |
| 329678. Has anyone gone from Remicade to Simponi? Any luck?? |
| 330947. Hey guys! After failing all medications including Remicade I'm finally scheduled for J-Pouch surgery on Tuesday the 21st. I'm pretty nervous. I've been given the rundown by my surgeon but if anybody here has a J-Pouch and can tell me their experience I would appreciate it! I'm not entirely sure what to expect afterward, how I'll feel, how much it'll hurt and how hard the ostomy bag is to get used to. |
| 332158. Since I began remicade, I can't sleep at night. I feel tired ALL OF THE TIME, but can't sleep. Does anyone take anything at night to help them sleep? Thanks! FnegSDtired |
| 332360. Hello! I am switching from remicade to humira because of cost issues. I have been on remicade for about 5 years, and its unfortunate I have to switch. Any advice from anyone who has switched? Would love to know more about it! :) |
| 332737. Hey I've had Crohns Colitis for just over three years now, and I take Remicade every 8 weeks. I am planning on change it to every 7 weeks next time I see my doctor because I get run down by the end. However, I've recently experienced these awful headaches alike a pressure build up that hurts so much I am in tears. I'm sure you're all aware that with our condition, our pain tolerance is pretty high, so when I mention this, it's with the utmost concern. It usually occurs at night, and I wake up often ranging from midnight to 4am and have to take Tylenol 2 for them to ease enough to go back to sleep. Should I be worried? FnSDheadaches |
| 338427. Hellllloooooo IBD family. On Monday I posted about going in for Remicade. It was also my 1-year anniversary of starting infusions. The good news: after finally moving to 6-week intervals, Remicade is working! I am in the same boat as some of you with having an allergic reaction, but it's manageable for now. Some of you also posted about new meds and protocols you're trying like Simponi, Embrel, Stellara trial, the SCD lifestyle, and soon-to-hit market Vedolizumab. Please share your stories and what's working for you meds, diet, lifestyle changes - Ready Set Go! \*Jai\* FnSDallergic |
| 338758. Who's got two thumbs and is on her way (in the passenger seat; texting and driving is bad mmmkay) to a Remicade infusion? This gal! Anyone else, today? |
| 341454. Anyone on 6-mp and remicade taper off after a year of doing well? Thanks! |
| 342192. Kasaundra asks: Hi can you repost! Dr wants to start me on humira or remicade, but with my insurance both are pretty pricey. Does anybody know of any discount programs that will help pay for these medications? |
| 342851. Has anyone gotten LASIK while on Remicade or very low occasional doses of prednisone? |
| 344795. Ok need help or info. Dr recently gave me the options to go on Humira or Remicade. They both scare me with the side effects etc. just wondering what peoples experiences were on either of these please!!! |
| 344904. This is a question for those of you on biologics such as Humira, Remicade, and other "tumor necrosis factor" medications. How do you handle your fears about the drugs' increasing your chance of getting cancer by 300%, heart problems, and all those other horrible, life-threatening side effects it has? Or all those warnings overblown? |
| 345191. From Sarah: Can you please post a question for me. I been on remicade for two years now if just started seeing a RA for joint pain. She said the remicade isn't helping with joint pain so she wants to stop it and start another med to help my crohns n joints. She is Callin my GI to talk with him but I'm scared to stop my remicade bc it helps so much with my crohns. Had anyone else stopped a med to try another to help both issues. I no once I stop remicade I can't go back on so I'm worried. She told me also I would have to wait to start a new med till recimade was totally out of my system so I no if I don't get it in two weeks I get sick right away. Any suggestion on wat I should do!! Thanks FnegSDpains |
| 345222. From anonymous: I wanted to see if people would share their experience with partial bowel obstruction. I think I may have one. I had remicade last week and have been a little constipated. Last night my stomach was gurgling and I had horrible pain that came in waves for 5 hrs but no vomiting. I didn't want to go to er for them to say I have gas but the pain had me in tears. I'm scared to eat today. FnSDpains |
| 346312. After 2 months of being sick, losing half of my former self, down 2 surgeries, tomorrow I go in to my GI to talk about meds. My surgeon keeps throwing remicade out there. Can I get some input on it and side effects? I'm currently on lialda (sp?). 1 surgery was an abscess, the second was for a fistula that made me look like I was carrying alien offapring. Suggestions would be greatly appreciated... |
| 346353. From Rebecca: Has anyone ever experienced a red raw tounge directly down the center? This is new to me I've never had this before. I have been diagnosed with Crohns 18 months ago and currently on Remicade and Pantessa. Been undiagnosed for many years. Thank you |
| 346686. So I found this group while sitting in the hospital with my son who has Crohn's... can anyone help me with understanding of Remicade and what your thoughts are of it? FnSD leg cramps |
| 347887. From Kendra: I need some advice ASAP. I've been on remicade for cd for over a year. I missed my last infusion a month ago. Both my ankles have been swelled bad for a week pic included. Could it be missing that dose be doing it? I've never had any issues with Remicade before. ThxFnegSDedema |
| 347944. From Rebecca: Could you please post this would love some feedback. I went today for a colonoscopy, just had one 6 months ago however been having some severe flares. Today he tells me that my small intestines are narrowing due to years of inflammation. Now have to have an MR Entrography done on Christmas Eve. My question is has anyone ever had this or similar issue? If so what was your outcome? He said may have to have surgery depending on severity of the narrowing. Will know more when he gets the results of the MRE. Thank you all in advance for sharing with me. I am many years undiagnosed the last 1 1/2 diagnosed on Remicade Infusion now every 8 weeks and Pantessa 500 mg 6 times a day along with numerous other medicines to help control it. Rebecca |
| 348312. From anonymous: I need some advice. I've had a fistula from cd. Remicade isn't work. I know this is WAY too much info but I gotta talk to someone. I have no control over bladder n if I sneeze cough laugh I poop n pee on myself. I'm so embarrassed. I'm supposed to find a colorectal surgeon. I'm 38 n I have to wear adult diapers in case I'm out or overnight. I'm so sry. MSG is so graphic n long. Thx. Pls keep anon. #ashamed |
| 348872. From Jamie: Hi can you please post a question. I am starting on remicade soon. I was wondering what to expect.? And what other peoples experiences were? |
| 350418. Im In A Never Ending Battle With My Insurance To Get My Remicade. I Have Medicaid Hmo Freedom Frist. Any Ideas Please |
| 372916. Last December I had my colon removed cus I had colitis. Was suppose to be cured right. In September, I was diagnosed with crohn's disease. I read the posts on here about being misdiagnosed. My doctor still says I had both. So confused. Any advice for where to go from here? Drugs never worked for me and had severe allergic reaction to remicade. Feel very lost with all this. FnegSDallergic |
| 372952. So I have been weaning off the endocort & today I took the finally dosage. I also went & got all my blood work done & chest X-ray for possibly being put on remicade. The scariest part is being on NO meds til my next appt in Dec !!! I have to admit, I'm scared !!! Any advice ?? |
| 374207. For those of you on Remicade. RemiStart may be able to help you with payment. This program from AccessOne makes rebates available to eligible patients to cover out-of-pocket Remicade medication costs. For details call 888-ACCESS-1 (888-222-3771) Monday through Friday 8AM to 8PM  . |
| 376662. My daughter has Crohn's and her doctor wants to try IV Entyvio. She has tried Humira and Remicade with only bad side effects. Can anyone tell me their experience with IV Entyvio? TIA FnegSDn |
| 377894. Are you or anyone you know on chemotherapy drugs such as remicade (infliximab) or methotrexate to help treat Inflammatory Bowel Disease (most commonly Crohn's disease or Ulcerative Colitis)? #IBD #Medication #Chemotherapy #Crohns #Colitis |
| 382593. Have any of you tried the infusion drug Remicade? I tried it last year and the nurse forgot to turn the drip down and it caused an enzyme problem with my liver. Now I am going to try it again with a lesser dose. I'm praying this will work, nothing else has. I'd love to hear of anyone who uses this.FnegSDn |
| 24181. Has anyone had a treatment called Infliximab to treat their Crohns ? NA |
| 28049. Rajiv Jeebun Dear Admin, Please post this on my behalf as I want to remain anonymous. Thanks I need to draft a statement in regards to my disability. I am been diagnosed with crohn's since January 2011. I had severe flares up. I have use asacol, prednosilone, methotrexate, azathioprine, mercaptopurine and also infliximab. I was discriminated against my illness at work and need to write a statement. Please any kind of help and support or ideas will be much appreciated. I need to write and confirm that crohn is a disability for me. Also been diagnosed with osteoprosis since april 2012. What I need to be included in the statement is information setting out the effects on day to day activities of IBD, desrcribing duraton of those effects. Also I have to indicate what would be the effects upon me if i do not take the medication prescribed to me. NA |
| 28151. Inflamed and Untamed Welcome! My name is Sara, and I don't have a large intestine, but I DO have a large amount of passion for spreading awareness about Crohn's disease and ulcerative colitis! Diagnosed with UC: 1996 J pouch surgery step 1: july 18, 2008 J pouch surgery step 2 and adhesion removal: September 10, 2008 Diagnosis changed to crohn's: June 17, 2011. Tried too many meds that failed, currently doing remicade infusions and methotrexate injections. Hello, my name is Sara and I have Crohn’s Disease! \*\*This post is edited. It was originally from the HAWMC (that I never completed) where I was asked to introduce my disease to people who don’t know about it. Updating and sharing again! 1. My name is Sara. I do go by the name Sadie though often now in my real life. It all started at my job where there were 5 other people who had the name Sara. They call me Sadie there which is a nickname of Sara. Now we have six people there with my name! Other names I am commonly referred to are: Ringer, Ringo, Sara Sally Ringo Raphael, and Squirt. You can thank my mom for that last one. <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/1.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/1.jpg" alt="1" width="500" height="419" class="alignleft size-full wp-image-782" /></a> Hello. Here is my face. Now you know what I look like. Well what I look like in bright lights and makeup, anyway. 2. I have Crohn’s disease (i’ll get to that in a bit). I also have a j-pouch, a motility disorder, and autoimmune arthritis. I suppose I could tell you the little things like I currently have a hernia and gallstones but those are just the little details. 3. I work at a salon. And by work, I mean I go there when I am not in the hospital or not out for long periods of time due to my disease. I’m sure you other health activists know how that goes. My boss is amazing for that, and I found a real passion in what I do by chance. I have my disease to thank for that! I do nails and makeup there and it is fan-freaking-tabulous! I also manage the social media of the salon. I’m a hard worker, I always have been and I always will be¦unless something is preventing me from doing so. 4. I have an animal problem. No seriously, I am pretty sure if people were not around to stop me that I would have 4 dogs and 7 cats by now. Luckily someone is always there to stop me¦most of the time. That is how I wound up with my big German Shepherd dog, Scout. I went to the Humane Society to maaaaaybe get another cat. I felt like my cat, Ludacris, needed a kitty friend so I went there to scope out the felines. I took a wrong turn and wound up near the dogs and that is when I spotted a 7 year old German Shepherd who had bandages on both legs and a head cone. He also came with anxiety meds and prednisone. I came home with him! Oh btw, I have never had a dog of my own before then. There are 3 horses and a donkey for sale right now at the Humane Society¦ 5. I have an incredible memory. I love to read. I LOVE the Harry Potter series books (movies are okay but the books¦omfg) and I am convinced I am in the house of Ravenclaw. If you are rolling your eyes right now then it’s obvious you’re a muggle. Unicorns are fun. I like to eat cake. Sunshine makes me happy. I have the imagination of a 5 year old but at the same time I am a very old soul. 6. I was a dancer for a huge portion of my life and then went on to teach and choreograph. I had competitive dance students that went to local and national dance competitions. Think Dance Moms except I wasn’t a big and mean teacher. I was small and loud! While I worked as a dance teacher I had a second job as a cake decorator. I was the lead cake decorator for many years in the bakery. 7. I am terrible with technology. No for reals you guys. It’s a wonder I know how to operate this blog. I learned how to edit videos in the past year and use the easiest program for everything. I am apparently good at fooling people because everyone thinks I got skillz! Y’all, I can’t even operate my remote control! I still don’t understand google analytics fully and have no idea how many people actually read this blog. I like to stay in the dark and pretend like I get thousands of hits a day. ;) 8. I have a chauffeurs license. I could drive a limousine, taxi, or a small school bus if needed. 9. I love snakes and all cold blooded animals. At one time my brother and I had 15 pet snakes because the snake we had had babies! 10. My favorite kind of food is tied between Thai, Indian, or sushi. I love socks but hate to wear anything on my feet. I have a biggest heart but it’s hard to knock down the walls I’ve built up to get to it. I love laughing, I love to learn, and I really love to travel. I hate cold weather. I don’t understand hatred, violence, or the evils of the world. They can get me pretty down. All I want to do is leave my mark on this world and make it a better place for at least a few people and in return all I require is feeling happy, safe, and content. I never want to stop learning because once you stop learning you stop growing. I also never want to stop teaching. I’m pretty fricken silly most of the time. Okay, WEGO told me to introduce my health condition to you all. So now here we go for real: Hi, I’m Sara, and I have Crohn’s Disease. I don’t have any of my large intestine or rectum left (ewwww, she just said rectum!). Did you know you could live without your large intestine? I didn’t until I got sick. Fun fact: Your large intestine and your colon are the same thing. I use the words interchangeably on purpose because of that fact. If you didn’t know before, now you do. I have no colon. I have no large intestine. Same thing. Ba-da-boom, ba-da-bing! <”-I just wanted to say that. <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/2.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/2.jpg" alt="2" width="500" height="515" class="alignleft size-full wp-image-783" /></a> (I like to make IV’s look fashionable. hahaha) I have a J-Pouch. It’s pretty cool you see, I’m kind of like a marcupial except I don’t carry my babies in my pouch. I carry my¦. nope. Not going there. So as I said, I don’t have my colon. Instead the end of my small intestine has been reconstructed and turned into an internal reservoir and is attached to my anus (Crohn’s disease is the sexiest of dem all!) so that I can use the bathroom just like everyone else. To get my j-pouch I had to have two major operations that came with a lot of pain and complications. A normal persons insides look like this: <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/3.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/3.jpg" alt="3" width="500" height="643" class="alignleft size-full wp-image-784" /></a> Mine look like this: <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/4.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/4.jpg" alt="4" width="493" height="335" class="alignleft size-full wp-image-785" /></a> Like I said, sexiest disease of them all! To read more about my j-pouch and what it is you can read this blog I wrote: http://www.inflamed-and-untamed.com/post/24890754880/what-is-a-j-pouch \*So here is what you need to know about Crohn’s disease. A lot of people have the misconception that it is just like IBS. If I can get you away from one thing it would be this. Crohn’s disease is an inflammatory bowel disease. IBS is Irritable Bowel Syndrome which sucks, but is a much less serious condition. Another misconception is that it has everything to do with stress and diet. Listen peeps, if I could have saved my large intestine by changing my diet and controlling my stress, you better believe I would have. This is an autoimmune disease, just like Lupus, Rheumatoid Arthritis, and all the other autoimmune funtime body games. My disease attacks my digestive system but it also has what are called œextraintestinal manifestations". Meaning a lot of people with Crohn’s disease also have issues outside of the digestive system like arthritis, eye problems, skin problems, liver problems, and so on. I have arthritis that can often be debilitating. It’s awesome being young and feeling old. No, no it’s not! Crohn’s disease can attack your mouth, esophagus, stomach, small intestine, large intestine, and rectum (I am finding every excuse to use the word rectum). When I am sick my remaining intestine becomes inflamed and starts bleeding. It’s not uncommon for people with my disease to need blood transfusions from bleeding internally. I have received some blood transfusions myself. This bleeding also causes a person to become anemic which causes extreme fatigue and so on! When my intestine is bleeding and inflamed it hurts to eat. It hurts to eat ANYTHING. Sometimes it even hurts to drink water. I also don’t absorb nutrients well during those times and lose weight rapidly. That also contributes to the major fatigue I often feel. There have been times when I have not eaten any food by mouth for weeks or months at a time. I am put on something called TPN which is nutrition that is given to you through a PICC line. Sometimes patients are put on this to give the bowel a œrest". Sometimes patients are put on it because they are not able to absorb nutrients when they are so inflamed inside that their intestine isn’t able to absorb what they are taking in. Sometimes we are put on it because of something called Short Gut, which means that so much of the digestive system has been removed through multiple surgeries that they now don’t have much of it left. There are a number of reasons why Crohn’s disease patients are put on TPN. Surgeries are something a lot of us are faced with. Sometimes the whole colon has to be removed or sometimes patients have portions of the small and/or large intestine removed. For patients with Crohn’s disease the likelihood of the disease coming back near the portion of digestive tract that was removed is high, therefore multiple surgeries are sometimes required over a lifetime. <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/5.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/5.jpg" alt="5" width="500" height="375" class="alignleft size-full wp-image-786" /></a> (After a surgery) Some patients experience painful blockages. I have been hospitalized many times for them and have had a surgery to resolve one. Blockages can occur because of something called strictures, which are a narrowing in the digestive system caused by scar tissue. The scar tissue is the result of periods of inflammation and healing over and over which hardens the intestinal wall and it thickens. Blockages can also be caused by adhesions due to surgery and a number of other factors. Sometimes these blockages heal on their own, other times a patient requires hospitalizations for pain medications and fluids or nutrition until it passes, and sometimes surgery is required. Some patients experience fistulas. This happens when an ulcer in the bowel penetrates through and creates a tunnel from the digestive tract to another area in the body. This tunnel can lead to the skin or to other organs. Sometimes an abscess occurs due to the fistula, which is a very serious infection. A number of different medications are used to treat Crohn’s disease. I go to the hospital every 7 weeks to get an infusion of a drug called remicade. Remicade is a biologic and works like chemotherapy to suppress the immune system. I also inject myself with methotrexate, which is a chemotherapy that also suppresses the immune system. Because of this I have to be extra cautious around sick people. I also worry about the potential life threatening side-effects of these medications. Steroids are very common in my community, which also have horrible side-effects. Other patients use different types of anti-inflammatory drugs. A lot of times finding the right medication for the patient is a guessing game. We are all a bit different and respond differently to treatments. What is even more confusing is that a medication can work for a patient for a long period of time and then just stop working. Some patients don’t respond to any medications they try, and some patients choose to not take medication at all. Symptoms vary from patient to patient. The most important thing to understand is that every Crohn’s disease patient is different. Some of us have the disease very mild, others very severe, and everywhere in-between. You might meet a Crohn’s disease patient who has an ostomy. This is often a life saving surgery where the intestine sticks out of an opening in the abdominal wall called a stoma. The patient has no control over the things that move through their digestive system and therefore a bag has to be attached to the stomach around the stoma to collect waste. This is not gross and these people are not to be feared. Take a look at my sexy friend and fellow Crohn’s disease advocate Jess Grossman who is working so hard to squash ostomy stereotypes. She’s hot and she shits in a bag. So what! <a href="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/6.jpg"><img src="http://whatiscrohnsdisease.co.uk/wp-content/uploads/2013/06/6.jpg" alt="6" width="402" height="604" class="alignleft size-full wp-image-787" /></a> It’s not uncommon to experience anxiety and depression from living with Crohn’s disease. It’s exhausting both physically and mentally! Medications cause changes to our bodies such as weight gain, weight loss, hair loss, moon face, psoriasis, acne, arthritis, and so forth. These changes to our bodies are hard to handle because we have to take the medications and have no control over the effect they have on us. Surgeries alter the way our bodies look and function which is a major adjustment. Frequent hospitalizations and uncertainty in our life plans cause major anxiety and fear of the unknown. We often feel embarrassed of our disease or symptoms and isolate ourselves. When we are bleeding internally or inflamed we become tired and our bodies are working extra hard fighting a disease. That, medications, and other things make life with Crohn’s disease often exhausting. We may cancel plans or seem like hermits at times. The cool news is some patients respond to treatments or surgeries well and are able to live happy and full lives. Others do not. It’s all a wide range of how the disease will affect a patient. This is just a liiiiiitle bit about life with Crohn’s disease. That may have all sounded scary and depressing (truth is some of it is) but my disease has taught me a lot of life lessons. All I can do is do my best and keep putting one foot in front of the other. I look at life a lot differently than my peers and I think it’s a blessing. The thing I want most people to know is that I don’t want pity and I don’t want you to be afraid of me. I’m pretty cool - I’m funny, smart, and interesting (hopefully) and I make a pretty great friend. I just also happen to be sick. So that’s me and my disease. Now I am off to meet all of you! -Sara |
| 29323. Hi there was wondering if liver cirrhosis can be connected to crohns disease? I had liver cirrhosis for months and even had a scan and after a while everything went back to normal though the reason im asking is around 6 years ago i was taking infliximab to treat my crohns then i kept passing out etc to be then told i had drug induced lupus due to the infliximab. Then i was told not long ago that i have fibromyalgia and i think it's lupus 'sle' and that i always had it. Does anyone think this is possible and that my crohns meds have been keeping it at bay or hard to diagnose ? Would appreciate all feedback. Thank you, Amy xx FnSDcirrhosis, lupus,fibromyalgia |
| 32090. I went in for a infliximab infusion today as I'm having a flare up, I'm also on predisolone, eg steroids ! How long should it be iff I notice a differance from the infliximab? Anyone no?? Xx NA |
| 63761. Has anyone any experience with infliximab? Am just about to start on it. NA |
| 71224. La Comisiƒ³n Europea ha autorizado Remicade (infliximab) en el tratamiento de la colitis ulcerosa activa grave en pacientes pediƒ¡tricos de 6 a 17 aƒ±os que han presentado una respuesta insuficiente al tratamiento convencional. NA NA |
| 140404. My daughter Hannah was diagnosed with Crohn’s at the age of 10, she is now 17. She was seriously ill by the time her diagnosis was confirmed because it took so long. Her treatments have included steroids, elemental drinks, Infliximab, 6-MP, Methotrexate, etc. etc. None of these treatments have worked. Fortunately we found a website “ The Chronic Crohns Campaign “ which included details of the work of Professor John Hermon-Taylor. For us, his explanation of MAP bacteria causing Crohn’s made absolute sense; we had spent years refusing to believe that such a condition can appear from nowhere without any trigger at all. Hannah was lucky enough to obtain the treatment of Rifabutin and Clarithromycin, both designed to have a specific action on the MAP. The treatment worked excellently for Hannah and she was absolutely normal for 2 ‚½ years. Unfortunately, the MAP is an extremely virulent and clever bacteria and it worked its way around the medications and started to get the upper hand again. Having tried Infliximab and ending up with anaphylaxis and it not having any benefit at all, Hannah was then put onto a triple therapy treatment (as favoured by Thomas Borody who has worked closely with John Hermon-Taylor and was part of the team which proved stomach ulcers are caused by a bacterial infection - the medical profession refused to believe such a theory “ sound familiar?) of Rifampicin, Ciprofloxacin and Clarithromycin, together with a tiny amount of 6-MP (which is believed to have some anti-MAP action) and she is currently doing great. Hannah’s story shows that there is medication which can actually treat the ROOT CAUSE of this disease, rather than just treating the symptoms, and also that MAP is most definitely the cause of her Crohn’s. But her medication is not a cure, it is a temporary fix which will need to be tweaked, adjusted and always there is looming in the background the terror of nothing working any more and then major surgery becoming the only thing on offer. A vaccine which teaches your own immune system to recognise the MAP is a wonderfully simple solution and it has been proven to work in both mice and cattle. I am fundraising for this vaccine because I believe 100% it is a cure for Crohn’s and I would give anything for my beautiful daughter to have the chance of a normal life free from toxic medications and the constant worry of a chronic illness. Through fundraising for the vaccine, we have met some wonderful new friends and it is the silver lining in the Crohn’s cloud that something positive is coming out of something so negative. The real |
| 152408. It was hospitalisation and a passion for knitting with goats’ hair that put Dr Judith Liipton on the path to anti-MAP therapy. She has now been in remission for 10 years. Read her story here and learn why she believes, as we do, that only crowd-sourcing, the power of the people, has the potential to overcome the self interest of the market place. "In 2004, I nearly died of septic shock as a result of penetrating abscesses in my colon, secondary to Crohn's Disease. I was hospitalized two times, the second time because I broke through conventional treatment with steroids, azathioprine, and Remicade (Infliximab). As luck would have it, I am a knitter and had kept fiber goats. I knew about Johne's Disease. So as I was recovering from the second hospitalization, I read that Crohn's could be considered a human form of infection with Mycobacterium Avium subspecies paratuberculosis (MAP), the same pathogen that causes Johne's Disease in almost all other mammals. I was able to connect with Prof. Thomas Borody, of Australia, and subsequently convince my primary care doctor in Seattle to try Prof. Borody's treatment plan for Crohn's: not anti-inflammatory drugs, but medicines targeted against multi-drug resistant tuberculosis, including rifabutin, clarithromycin, and clofazimine. I took my first dose December 10, 2004. I am writing this nearly 10 years later, and have not had any symptoms of Crohn's Disease or colitis or any gastrointestinal disturbance in almost 10 years since starting anti-MAP antibiotic therapy. Dr. Borody, from Australia, is a close colleague of Prof. John Hermon-Taylor, from the United Kingdom. Together, they have pushed the boundaries of treating Crohn's Disease to a whole new dimension, for which the whole world should be grateful. I don't think I would be alive today were it not for these good doctors. I had the honour of meeting Prof. Hermon-Taylor at the American Association for Microbiology special meeting about Crohn's Disease and MAP in 2007, and I have followed his work ever since. Prof. Hermon-Taylor is working very diligently to create a vaccine against MAP. This is extremely important, because MAP has been found not only in animals used for food or milk, but also in drinking water, showers, and biofilms throughout nature. While I continue to believe that it is a crime to allow animals with Johne's Disease into the human food chain, I understand that there are other natural reservoirs for MAP. A vaccine that would immunize individuals who lack the proper natural immune forces to kill MAP would greatly benefit humankind. Probably around 4 million people worldwide now have Crohn's Disease, with increasing numbers in South America and Asia, populations that did not previously show huge numbers of inflammatory bowel disease patients. Unfortunately, the medical establishment, including physicians and the pharmaceutical industry, have a lot invested in the so called "autoimmune" theory of Crohn's Disease. They make billions of dollars treating Crohn's as though it is a war of the body against itself, rather than a war of a pathogen against a host. In addition, the meat and dairy industries have a lot to lose, if they were to identify MAP as a human pathogen. The numbers of animals infected with MAP in Europe, Canada, and the US make Mad Cow disease look trivial. Prof. Hermon-Taylor's work directly challenges Big Medicine, Big Pharma, and Big Food. So it is no wonder that he has to struggle with paltry funding, while fancy new drugs that support the status quo get the research dollars. Prof. Hermon-Taylor is a medical pioneer, a brave man, and a genius. Please help to support his work! Neither governments nor industry is going to get this work done! If you have Crohn's Disease, or you love someone with Crohn's Disease, this work affects you directly. It is a clear case where only crowd-sourcing, the power of the people, has the potential to overcome the self interest of the market place." If you would like to read more of Dr Lipton's story, please see https://www.psychologytoday.com/¦/is-there-cure-crohns-part¦ IT'S TIME TO CURE CROHN'S! http://crohnsmapvaccine.com/ https://www.justgiving.com/CrohnsMAPVaccine-MEN9150/ https://www.justgiving.com/teams/crohnsmapvaccineheroes #crohns #crohnsdisease #IBD #crohnie #crohnsvaccine #MAP #curecrohns |
| 158447. My first operation when I was 21 when I perforated my bowel & had emergency surgery. No bag required. I am now 28 & I have been having issues with my crohns since Feb of this year...seemingly getting worse not better - have just finished my course of IV infliximabe (Remicade) to which it failed. So I am now booked in for surgery on the 20th of this month and surgeon thinks very high possibility of a bag. Just after some advice or what to expect with a bag - thanks. |
| 167431. Em's Question: "Has anyone Tryed herbalife diet when having Crohns ? Also would it cause any problems if your on infliximab infusions ?"NA |
| 176292. Whats peoples views on Infliximab? I was diagnosed in 2000 was put on mezazaline although diet controlled it. I have had 3 children and after each CD got worse. Was put on Azathioprine and when i have had a flare was put on prednisalone and now have just finished 3 mth course of entocort. This has made no difference and after having tests was told that my calprotectin levels are way too high. So clearly not responding to these meds. Have received a letter today from my specialist stating they want me to start Infliximab. |
| 176408. Hi all, have a few questions I have Crohn's disease and have only been diagnosed 2 years. My crp marker at its lowest since diagnosis was 34 so all the meds they've had me on hasn't worked very well, I have to have another colonoscopy and if still bad they looking at putting me on infliximab ?? Which I don't really know much about ??. Can someone tell me?. Another thing is I had to see my gp again today as I have bad numbness in my left leg to the point my leg has given way causing me to fall in a heap on the floor . They not sure what's going on so r referring me for mri on my leg but she did say could b lacking vitamin b12? Is this a symptom and how is it treated etc?? Hate crohns with a passion!!! |
| 180349. Hi everyone , how is everyone today. I hope no one is suffering to much , my boy Lewis is doing really well a the minute his infliximab and azathioprine seem to be working, I've decided to raise some money for crohns u,k but need the word spreading by everyone I'm making some dog bandanas and all proceeded bar the cost of material will be donated to this cause to help either find a cure or better treatments to make life easier and pain free were we can , we have lived with this disease for four years Lewis was 2 when he started with problems he was do when he was. And now 6 he's thriving and being happy like a normal little boy . Any information or to look at the bandanas please go to my doggy day care page Molly moonshines , or the link is on mollymoonshines.co.uk. Les aise as much money as we can.xxxFpSDvp |
| 184972. Hey guys, been a while - looking for some advice.... My Husband takes mercaptupurine (6mp) and has been having the "deja vu episodes" for some time. The only connection i can find is mercaptupurine, as he has been having these episodes for a few years, even when he was taking infliximab infusions, but is now self injecting with humira. My question is: does anyone else suffer with these syptoms? Thanks all xxxFnSDdeja vu????? |
| 201655. Stor fransk hospitalsgruppe vƒ¦lger biosimilƒ¦rt lƒ¦gemiddel - 45 % rabat Det biologiske lƒ¦gemiddel Remicade, har mistet sin patentbeskyttelse, og nye versioner af lƒ¦gemidlet er dukket op. De sƒ¥kaldte biosimilƒ¦re lƒ¦gemidler, der har samme virkningsstof som originallƒ¦gemidlet - dvs. "Infliximab". Den franske hospitalsgruppe, der servicerer en fjerdedel af den franske befolkning, vil fremover behandle autoimmune sygdomme (som fx Crohns sygdom) med den billigere "Infliximab"-version, og ikke det velkendte brand Remicade (der i Europa har en ƒ¥rlig omsƒ¦tning pƒ¥ cirka 15 mia. kr.). Priserne pƒ¥ biosimilƒ¦re lƒ¦gemidler varierer, og er afgjort med til at fremme udbredelsen af dem. Norge har fx forhandlet sig frem til en rabat pƒ¥ 69 %. Flere andre biologiske lƒ¦gemidler mister snart deres patentbeskyttelse, sƒ¥ der vil dukke endnu flere biosimilƒ¦re lƒ¦gemidler op pƒ¥ markedet, og helt nye problemstillinger. Du kan lƒ¦se meget mere om biosimilƒ¦re lƒ¦gemidler i det kommende CCF Magasinet (CCF's medlemsblad), og ikke mindst lƒ¦se om CCF's holdning til brugen af dem. Lƒ¦s mere om den franske hospitalsgruppe (engelsk): NAhttp://www.reuters.com/article/2015/07/07/us-france- biosimilarsidUSKCN0PD1SI20150707 |
| 216677. Boa notƒ­cia!!! Atƒ© pouco tempo apenas o Remicade/Infliximabe era liberado para tratamento da retocolite ulcerativa no Brasil. Mas em outubro o Humira/Adalimumabe tambƒ©m foi liberado! Leia mais em: http://crohnecolite.com/humira-liberado-para-retocolite-ulcerativa NA NA |
| 218423. Primeira infusƒ£o inflixima NA |
| 221664. Boa tarde. Pessoal, alguƒ©m sabe onde posso tomar Noripurum na cidade de Guarulhos? Meu medico me disse pra procurar por centros de infusƒ£o, mas ainda nƒ£o encontrei. Se alguƒ©m do grupo puder me indicar local para pegar medicamento de alto custo (azatioprina e infliximab) agradeƒ§o. NA |
| 224110. Joe on his infliximab infusion on Tuesday just after being told he is in remission!!!!!FvpSDn |
| 224147. Am really looking forward to this Sunday 12th July. Hubby along with 2 of our close friends are running the 10k vitality run in London. There will be lots of Cheers and celebrations after the run. Our 15 yr old son Joe got told he is in remission with his crohns on Tuesday. He will continue with his 8 weekly infliximab Infusions and azathioprine tablets but it means any pain he suffers now with his joints we can safely say it's his other genetic condition 'nail patella syndrome' of which he has arthritis. If you would like to sponsor Chris here is the link. FpSDjoints pain, arthritis |
| 224302. New Research Blog To read the latest Research Blog "Treatment with Infliximab may also be making your bones stronger", visit our Research Blog page: http://www.cicra.org/what-we-do/research-blog |
| 224777. I'm really struggling at the moment mentally with everything. Jamie's diagnosis changed to Crohn's last year based on the fact that the modulen feed he had worked. Since reintroducing food he started with symptoms again, but we couldn't pin point anything in particular..... It seems to be all food. So back on the feeds he went. Mixed with eating food for pleasure. If we stop the Modulen his weight drops dramatically. I went along with the Crohn's diagnosis not quite believing it as how could they diagnose it without seeing it. In November he had another scope which showed some mild inflammation, not enough to change his meds, even though the meds he was on was not getting rid of the symptoms. Things carried on getting worse and his doctor decided to do another scope which happened a couple of weeks ago. The doctor saw active Crohn's disease though could tell it's been partially treated by the azathioprine, it's not enough and would recommend Jamie started infliximab. I know it's not about me, it's about Jamie. But this news has hit me hard. I was convinced it was still UC. I don't know how to help him. There are no support groups here in Preston, no one to talk to and share experiences. No one Jamie can talk to in his age group who has IBD. It is very lonely, very frustrating and very stressful. There is no outlet for either of us and we both feel overwhelmed. Our life consists of hospital trips, toilets and pain. Jamie feels too ill most of the time to do anything. I know it's not good for him, he's letting it win and I don't know what to do to help him. Sorry for going on, I just don't know where else to turn. I have said before I would be happy to set up a support group in Preston for children with IBD....but letting them know is hard, as we wouldn't know how to let them know. |
| 225577. A huge 'thank you' to Angela for sharing her story. Molly was diagnosed with extensive Crohn's Disease when she was 12 years old, she is now 16 and an amazing and inspirational young lady. Here is the next part of her story .... And so began the first of so many treatments - 8 weeks of Total Parental Nutrition via an NG tube, Modulen, which had a dramatic effect as Molly regained weight, and some energy, and lost her deathly pallor. But by now she had developed the more obvious symptoms of persistent diarrhoea, and rectal bleeding, so she was started on Prednisone, and then Azathioprine at the start of 2012. Prednisone made her cross and gave her insomnia, and the risks of Azathioprine as a treatment with it’s vs. benefits caused our first of many bouts of anxiety over the drug therapies used for Crohns. We quickly learned that the side effects of drug therapies were often as distressing as the IBD symptoms, and brought along a whole host of new problems. There was a brief period of Molly feeling well after this, but then her bowel symptoms worsened greatly, and she was often too ill to go to school, so she was started on Methotrexate injections, given at home by Petra, the Community Children's Nurse who has become a warm and reassuring presence in times of crisis for Molly over the last 3 years, and a great support to the family. Unfortunately 6 months of Methotrexate didn't have any real effect apart from making Molly feel very sick, and then in April 2012 she developed a huge and terribly painful peri-anal abscess and had the first of two emergency surgeries in 4 weeks, to drain it and then re-drain it. An NG tube was inserted at the same time, to start another 8 week course of tube feeding to rest her bowel again. Molly had started Infliximab Infusions by now, the first of the Biologics, the Big Guns, which we were very excited about as it had such good results for so many people with stubborn Crohns. We managed, got into a routine, and grew even closer when we were there at 3am and 4am showering each night, but the loss of independence for Molly was disastrous. She could not leave the house in case she needed to go to the toilet, could not eat out, see her friends or go to school. And at 14 she couldn't explain why to her peers, Crohns was an embarrassing condition to have. She became socially isolated and very depressed. Already a shy girl naturally, the few friends she had drifted away, as she was simply never at school, and teenagers are not known for their empathy, so she was forgotten. We were together 24 hours a day as she became so anxious she often wanted me to sleep with her when she felt ill . She had developed palpitations which were worse at night, and cold then hot sweats, felt nauseous in the night, all drug side effects. All was not doom and gloom however, we managed to laugh at our situation as I helped her into the shower in the wee small hours. When she couldn't sleep we went for a drive in the car, singing away at Molly's JLS CD's! Initially the Infliximab worked well and Remission, that pot of Gold at the end of the Rainbow for all Crohns and Colitis sufferers, seemed to be coming for a visit. more to follow ....... |
| 225869. Read Charlotte's story ..... I first started getting symptoms of Crohn's disease in 2006 when I was 8 years old; however it took around 3 years for me to finally be diagnosed as my local hospital failed to work out what was wrong with me. I wasn't diagnosed with Crohn's disease until 2008 when I was 10 years old after suffering with a lot of abdominal pain, weight/blood loss and various other symptoms. I was transferred to the Norfolk and Norwich hospital as my symptoms continued to get worse. I was losing weight and my growth was stunted, I was also suffering with fatigue and my face appeared pale and thin, I was in a lot of pain every single day, especially after eating food. After many tests including colonoscopy's, blood tests, allergy tests, and various scans they confirmed it was Crohn's disease. I was placed on the supplement modulen milkshakes twice in one year to try and see if not eating any food for 6 weeks at a time would settle my symptoms but after this failed along with steroids and other medications, surgery was the only option. In November I went in for surgery to have part of my bowel removed but was told afterwards medication would be able to treat it so I returned home a couple of days later when my scars had healed. However the hospital were wrong, I was in so much pain I could barely stand up on Christmas day, let alone eat the lovely dinner my mum had prepared for the family. On the 6th January 2009 I was back in hospital to have the section of my bowel removed. The surgery was successful and since then my symptoms have calmed down. I am now on infliximab infusions every 8 weeks after I had a flare up a few years back, it completely changed my life and I was able to continue with my usual activities which was a major achievement for me. The infliximab is now beginning to lose effect so the talk of coming off the drug and on to another biologic is on the cards. A Psychologist and Physiotherapist have both helped along the journey with my Crohn's disease due to different side effects I was having. I still experience symptoms of the disease most days and since it has spread to my mouth it has caused a few more challenges to overcome in my everyday life; however I consider myself VERY lucky after reading what other people have been through and I will not let my Crohn's disease get in the way of my aspirations in life no matter what the future holds. Charlotte - age 16 years. .a |
| 231983. This small study shows patient experiences when takin Remacide (Infliximab) for Ulcerative Colitis |
| 232088. As anyone here used Infliximab? Any opinions on this article? |
| 262831. Boa tarde, gente! Hoje realizei minha oitava infusƒ£o de Infliximabe. Houve umas oscilaƒ§ƒµes na pressƒ£o arterial, mas isso ƒ© logo resolvido e no final deu tudo certo :-) Estou satisfeita com meu tratamento. ƒ‰ o que tem pra hoje e muito me ajuda. Sou grata ƒ equipe do CID MED Botafogo. Super profissionais e atenciosos. Em setembro tem mais! Visitem o blog! crohnadinha.wix.com/crohnadinha |
| 275592. Hey peeps. Ive been battling Chrohns for 20years now. Have been on prendisolone for majority of that even after surgery. Ive been on Imuran for a few years now. Im feeling ok at the best of times but I think you just get use to the pain. The docs are reviewing me for REMICADE -(Infliximab). Id really appreciate any feedback from anyone regarding this medication. Its a bit of a worry being on it long term as the side effects sound awful. P.s this is my first ever attempt of online advice..big step for me. Sending lots of Healing vibes to all your bellies ;) alli FvpSDn FvpSDn |
| 278275. I think this video is something that all Crohn's sufferers should watch it's called "Crohn's Controversy: Cause, Vaccine and Anti-MAP Therapy". Patients are being told they need surgery to move their entire colons and other parts of their digestive system, without being offered Anti-MAP treatment (which has been shown to have a 66% success rate - much higher than infliximab or any other known Crohn's treatment). The information within this video is broken down in incredible detail and debunks the failed Australian "Selby Trial" of anti-map treatment |
| 290631. Estimados por cambio de tratamiento biolƒ³gico de Humira a Infliximab estoy vendiendo una dosis de Humira. Quien utilice el medicamento o sepa de alguien que lo puede llegar a necesitar por favor comunicarse conmigo por inbox. Gracias |
| 298834. Off to acupuncturist today after a painful week. Hospital burnt off ulcer that hasnt healed and Ive had arthritic swelling in my legs. Surgeon suggests RA dr for testing and am seeing gastro dr next week who will suggest the same. Infliximab infusion is wearing off after 3 weeks which is not good. If I have to change this page to 'Crohns, Rheumatoid & me' it truly is a fucked up world. |
| 298892. Chilling to my fave music during my usual drug up. Has saved my sanity over the years. My eyes are like beacons again lol #infliximab |
| 299100. Interestingly my acupuncturist said if this joint swelling is a side effect from Infliximab she can't help me however if its my immune system playing up, acupuncture will help. Within the hour of treatment, I was able to close my left hand into a fist again and walk without as much pain! Very good sign. |
| 299104. Switching to 6 weekly for my Infliximab infusions as tests show its not staying in my system the 2 months. I am having aches n swelling joints when it loses its effect. Kinda sux but so does this awful aching. FpSDaches pains |
| 300258. Well I must say after over 3 years of either not working or working part time, full time hours is hitting me like a ton of bricks :P I have to stay on Infliximab for another 18 months and it zaps the energy levels too. It sucks, even though I'm well, I'm still restricted. .   aches pains |
| 300348. No fun having aching joints....and not like throbbing pain, I can't move my hands or arms or legs properly urrrrgh been like this for 2 days. Gotta get on the steroids tomorrow :( fuck it. I tried painkillers and valium last night and the pain wouldn't go. When I was very sick with Crohns I had arthritis in my legs and hands but that was swollen. This isn't. Weird. Spoke to my doc today and I'm at 5 weeks since my last Infliximab infusion and this is where I used to feel it wearing off when I was sick so this could possibly be what's happening now. #Disappointing. FnegSD aches pains |
| 300959. Day 33 n 5 nights in hospital with a wound vacuum dressing. Getting Infliximab infusion today as a preventative - Mrs Meds |
| 302651. Newer drugs for Crohn's disease - "ANTI" "F"or "C"rohn's \* Adalimumab--> Ada--limu--mab---> TNF inhibitor \*Natalizumab--> Nata--lizu--mab---> humanized monoclonal antibody against the cell adhesion molecule Ž±4-integrin \*Toclizumab---> Toc--lizu-- mabhumanized monoclonal antibody against the interleukin-6 receptor (IL-6R). \* Infliximab---> TNF inhibitor Fontolizumab---> Fonto--lizu-- mab---> a humanised anti- interferon Ž³ antibody \*Certolizumab---> Certo--lizu-- mab---> an anti-TNF-alpha mAb Courtesy : Dr.Prasad |
| 313684. Access to medication should not be a post code lottery. Please help by signing this petition supporting the use of infliximab in the UK regardless of which area you live in :) |
| 324948. Happy Friday the 13th.. Hi. My names Coral I'm 20 years old and I have Crohn's disease and have done for a few years now.. My mum also suffers with it too. I was misdiagnosed 5 years ago with ibs and went untreated for 3 years.. To eventually be told I 100% have Crohn's after 3 colonoscopys, MRI scans and so forth it turns out my disease has spread to 55cm of my ileum being diseased and 20cm active. I have been on every type of steroid there is and no luck only crappy side affects.. I have to have iron infusions due to being anaemic. I am now on azathioprine and infliximab infusions due for my 3rd one next month.. Unfortunately for me I've been experiencing uncontrollable pain in lower right side tummy and back.. I am now in hospital and this is my 3rd day.. I am on tramadol, codeine, paracetamol and oral morphine.. Yet I am still in constant pain. Was injected with steroids in the hope it would work and bring the inflammation down but it didn't. I now cannot open my bowels due to these tablets giving me a blockage. I find out later on today what will be happening with me so fingers crossed.. Happy flare up Friday and sending my love and thoughts are with every one else who fighting a daily battle.FnSDpains |
| 324952. Does anyone ever have an issue where Remicade does NOTHING that it's supposed to and gives you a flare up instead? I really don't wanna go to the ER today :/ |
| 342377. Jade asks: Hi, I was wondering if you could post a question to the page, I am hoping to hear from IBDers about their medicinal experiences as I cannot think of anything else! I have tried Prednisolone, Salofalk Mezalasine, Azathioprine, Budesonide and Infliximab and none have given me the relief I was hoping for. I have Pancolitis, please help!FnegSDn |
| 344639. I have been told that after nearly two years feeling really really unwell with abdo pain sickness diarrhea constipation, fatigue, after many many test main coming back negative one test for faecal calprotectine be extremely raised constantly after being on predesilone for many months that I do have some form of crohns and they plan to put me on Infliximab I know nothing about this drug is it some kind of steroid I am worried if it is as I am diabetic and it really messed my diabetes up when I was on prednesilone. any answers would be appreciated. |
| 345408. From Alice: Can you post please? Can anyone recommend anything to help, like anything. I'm on 150mg azathioprine and the trial drug usteknimab at the minute I've been on infliximab, adalinimab (sp?) And all sorts and nothing is working for me at all. I have vitamin B12 shots aswell. I have a two year old so I don't have the choice of lying in bed when I'm super ill. I have no idea on how to get more energy. Alls I've left the house for in the past 3 months is hospital appointments. Its getting on my last nerve because I want to do all these things with my son and I physically can't! Any help would be appreciated °Ÿ˜Š just even enough energy to take him the park. Or walk more than five minutes without needing the toilet. TIA xx FnegSDn |
| 345415. From Maarya: Hi, i have a question please can you post? I am starting Humeira on Monday; how does it make u feel? i am having my first dose first thing and am planning to go to work afterwards however i have no idea what to expect. I was on infliximab for 2.5years but about 3months ago my body stopped responding and i had a bad reaction 20mins into my last infusion so docs decided it was too dangerous to carry on. Am currently going through my 3rd flare up since i was diagnosed 8years ago. Thanks Fp e nSDn |
| 347823. I live with my fiance and 2 children under 5. My fiance has been very ill over the last couple of years. He has found it hard to leave the house due to constant pain sickness and diareah including blood in his stools.and when he did he was sent home from work. He was admitted into frenchy hospital and had to give up work as he couldn't cope. Since then in June 2012 he had a major operation to remove his bowl as he was told he had really bad ulcerative colitus. The operation was a nightmare what ever could have gone wrong went wrong in total he had 6 operations. I almost lost the love of my life and my kids almost lost there dad. He was in there for weeks very poorly. He has since then found out that he had crohns disease and still has it. He is in pain most days can't stand for to long can't sit or walk to long can Bearly pick up our kids or go for walks or go anywhere to far on his own. He is on atleast 60 pills a day to keep his body going including his heart (multi vitimums including magnesium) he is having infliximab infustions to try and get his disease under control. He has MANY illnesses and problems including joint and muscle problems, he has a permanent stoma, pancritis, tmj, ashma,dyhydration, vitimin d defencency nerve problems, blind in right eye' deaf in right ear, abdomen pain every day,open wound due to surgery, arthritis, tendonitus, sickness every day, his skin now burns because of his infustions and is very ill for days after, anxiety, low blood count low potassium and magnesium can't digest food properly and now thanks to e.s.a stress. as they have stopped his e.s.a. he kept getting letters to tell him to attend heath assessment with Atos which he did and was told it had been cancelled after he had hard trouble getting to the place. they never sent him a cancelled letter. this happened 4 times then he finally had an assessment and its all wrong. They havnt marked down half of his illnesses and have lied on the paper work did not do a proper check on him. His doctors and consultants have said he can not attend work any time soon. But yet e.s.a has stopped his money and left us down ‚£270 a fornight all we have is child tax credits and child benifits to surport a family of 4 ... We can not do this. I had to give up my job to look after him after the operations as he could not cook clean or anything. And I had to take care of my 2 children at the same time. I also suffer with really bad depression, anxiety and panic attacks this does not help us. He has been on the phone to d.w.p getting no where they don't know who's doing what. Different people keep giving out different information the information on their web site is wrong considering it was up dated in November. Did the benifits checker and benifits entitlement and put in all correct information and it clearly states he is entitled to either e.s.a or income surport but was told on the 9/12/2013 because we don't work we can't claim income surport??? He can't sign on j.s.a as he is not allowed to work and e.s.a has stopped his money but havnt closed his account so he can't claim j.s.a. please tell me how a family of 4 can live on next to nothing money? Lies and not correct information on a legal form is disgusting!! I have read online the problems people are getting of e.s.a and Defo Atos and now we are one of them. My partner has loads of proof of his illness and disease etc and has showed these people this but they didn't even put it on the form or anything!!! What is the point .Now my partner has been very ill since we got the letter on Saturday considering they stopped the money on the 3rd. If he has no money comming in how can he afford to get his very much needed medication as we have been told he could get fined if he puts his still on e.s.a but he can not live without it. How can he attend his very much needed hospital apointments including his infustions to keep him out of hospital. Our life over the last past 3 years has been a complete nightmare its been hell and on top of all his illnesses and his disease we now have to try and cope with hardly any money??? We are appealing against this but we have hardly any money in the mean time. What are we going to do. I believe this case needs looking into and we need help. He has had to go back to the doctors on the 9/12/2013 as the stress of all this has made him more ill and clearly states on doctors screen that he is not fit for work and has a doctors medical note/sick note to prove this. He is having side affects from his infustions and still has many many problems. This Atos place is disgusting. Why are they there? To hurt people and stop much needed money? They didn't even mark down most of his problems or medication well they didn't even listen to him properly in the first place. We are now very stressed worry and upset. We have emailed our local M.P to get some help. We are making complaints to Atos themselves and also appealing against e.s.a.... Has anyone else had this problem? X |
| 349395. From anonymous: Please has anyone else taken infliximab experienced horrific headaches? It's so painful I'm in years no pain meds touch it and its so bad. Ty x FnegSDpains |
| 371913. Has anyone ever had the treatment Infliximab by intravenous drip? .....i would like to hear of peoples experince of the drug and its effects. |
| 381248. \*\*\*Can anyone please help, we have a member needing some advice & support\*\*\* I am 29 years old, I was diagnosed 3 years ago, I now find myself in a position where my weight has almost doubled to a very very unhealthy 31 stone and I find it difficult to exercise because of the agony caused by my joints, I mean walking up and down stairs is a chore most days, and I hate the walking with my Girlfriend, as people always stare as she is tiny compare to me, and my clothes never ever fit properly anymore. My meds are imuran, infliximab, codeine phosphate, ibuprofen, steroids periodically. Because of the increase in my weight - I also now have trouble sleeping at night, as I stop breathing and get uncomfortable, causing me to wake several times a night which doesn't help my general tiredness. My consultant has suggested a gastric band as well as referring me to a rheumatologist. I'm not lazy or an overeater. I am 6ft 4, formally played rugby & kickboxed for many years, I have just fallen foul of circumstances, and I lack motivation now as I am also so uncomfortable both physically and mentally. Has anyone experienced this? Is this a good idea? Any other ideas? FpSDweight |
| 382581. Has anyone taken a reactiom to infusions - my last two trips to hospital have ended in me taking a reaction - 1st to infliximab and today ferrinject. Tiresome!! FpSDallergy tired |
| 386994. Please submit your responses to CCUK's recommendation that UCers should get access infliximab for moderate to severely active UC. Not all receive depending where they live |