

1/4/10

Hi. Well my dad's health took a turn last night and he is again in the ER/ICU. He is supposed to be going to Mayo Clinic on Wednesday but they are now wanting to do tests on him in Waterloo again. I will need to head that way this afternoon. I can be reached on my cell and I can check email at the hospital (they have computers). I will be in touch. Please keep him in your prayers. He went in last night due to the fact that he got coughing so bad he started to throw up and then with blood and he was even bleeding out of his ear (sounds like he blew his eardrum out). Ugh. I am really frustrated. I have left two messages for his doctor but feel like I just need to get there. THANKS, Jamie

1/6/10

I love the fact that there are computers all around at Mayo. I am currently waiting for my dad to come out of another test. He has a schedule for multiple days of appts (thru Tuesday). Today is a big one. Since my brother and sister-in-law are here, I am going to plan to head back to Dubuque either tonight or early tomorrow morning. So, I will either be in first thing in the morning or by noon. I will call and let you know. I am not too keen on driving home from here by myself late tonight, but I will check and if the forecast is ok, I should be ok. Thanks again for all the prayers. Now that we are here, I know they are going to find the answers. I feel like a weight has been lifted and everyone are so nice.

1/11/10

Hi all, Wanted to send you some updates on dad. Attached you will find a sheet with information that I sent to his doctor in Waterloo on what all took place last week. Hope this helps a little. If all goes as scheduled we should know on the 20th if he has the one thing they are looking at called Amyloidosis. But again, it isn't for sure yet that is what he has and even if it is, they will have to let us know which type it is. Thanks for all your prayers! Jamie

For information on the thing they are testing him for, here are some links:

<http://www.medicinenet.com/amyloidosis/article.htm>

<http://www.amyloidosisupport.com/ASGTRIFOLD2009.pdf>

<http://www.mayoclinic.com/health/amyloidosis/DS00431>

The copy from the attachment: Notes from dad's past week

On Sunday January 3, he went to Allen Hospital after getting into such a bad coughing spell that he threw up. He then started to throw up blood. Blood also came out of his nose and burst out of his right ear.

He was admitted to Allen.

The pulmonologist (Dr Shakoore) did a Bronchoscopy on Tuesday. He told me that there was no blood in the lungs, so he didn't believe the throwing up blood had anything to do with the lungs. He noted that he does have the slight pulmonary hypertension still. He also said he noticed blood in the sinus area.

A fatty stomach tissue biopsy was done on Tuesday also. This was ordered by Dr Kemmenova. She is a Hematologist/Oncologist. This was an initial step to see if dad had Amyloidosis.

Before he was checked out on Tuesday night, Dr Kemmenova stopped by and asked him to make a follow up appt to see here the following week.

Dr. Jaber (cardiologist) also came in. He was called by the Hospitalist to double check the heart enzymes. Dr. Jaber agreed with Dr. Kemmenova's assessment that it might be Amyloidosis. He said that going to Mayo is the best place to find that out. He also mentioned that the fatty stomach tissue biopsy might come back negative, but that won't mean he doesn't have it. Sometimes an actual biopsy of an organ is necessary, i.e. the heart or kidney. He said he would be willing to work with dad in Waterloo if needed. He is in the same office as Dr. Sbaity.

Finally left Allen around 8 pm Tuesday night and drove to Rochester. Dad's first appointment at Mayo was at 9:15 am on Wednesday with the Pulmonologist, Dr. Michael Krowka.

I went back into the room with dad and Dr. Krowka. He asked a lot of questions and reviewed the notes that were brought. He noted the heart issues: enlarged and the pumping capacity. He scheduled the first group of tests and appts and a few additional things were added by the Coagulation person and the cardiologist. This is the list of what he had done:

- Echocardiogram
- Electrocardiogram
- Stomach X-ray
- Chest X-ray
- Blood work
- Urine analysis
- More blood work
- Appt with ENT
- Eye appt
- Appt with Cardiology
- Appt with Coagulation consultant doctor
- Has additional tests scheduled for January 13
 - o Another fatty tissue biopsy
 - o Bone Marrow
 - o Additional blood work – double check factor 7

Notes from each appt:

Coagulation consultation

- He is the one that recommend the tests for the 13th
- Also noted his Factor 7 was off and gave dad medicine for that

ENT

- Said his throat looked good
- Did not see any blood in his sinus area.
- Has a hematoma in the left ear. Gave dad drops to get that to go down, so that they can get a better look at what damage is done to the eardrum.
- Has a follow up appt at Mayo on Feb 8th, but he was told the follow up could be done in Waterloo

Cardiology

- Talked about the enlarged heart and pumping issues
- Had results from both the tests
- Is anxious to find out more on the blood work and Amyloidosis to know the next steps

Pulmonologist

- Just asked a lot of questions and lined up appts
- Also felt like Amyloidosis is a strong possibility and wanted all the tests done and other appts done to see if it is
- He said knowing that will play a major role in how dad is handled

Eye Doctor

- Confirmed that back of the eye looks OK
- The bloodshot and bruising was due to the blood vessels/capillaries in the front bursting with the heavy coughing

Then the follow up appt with the Hematologist and with Dr. Krowka is set for the 20th

ITEMS:

- It was noted on his discharge papers from Allen to follow up with Dr Kemmenova. I told dad I didn't think that was necessary yet since he is seeing Mayo. Dr Kemmenova can help with treatment once diagnosis is made.
- He was also told to follow up with Dr. Jaber or Sbaity. Again, I told dad I didn't think that was necessary yet either
- Dr Shakoore wants info on what Mayo says

1/24/10

Hi everyone, I have placed you on an email list to get updates on my dad. As there are so many people that want to know what is happening with him and it is hard to call or explain to everyone, I told dad (and for my friends and coworkers) that I would do email updates.

Dad, mom, Marty (my brother), Dee (my sister-in-law) and I went to Mayo on Wednesday to get the results of the tests dad had done. It was confirmed that he has Amyloidosis. The type he has is called AL (primary) - which is a type of bone marrow cancer.

The relief of finally knowing what he has is great. Although, the process he now has to go through will be hard on him (and all of us). Since he is not stable enough (based on his age and the condition of his heart), they cannot do the stem cell transplant that you will read/hear about in the below links. So, he is on an oral chemo treatment. He takes 9 chemo pills in the morning on an empty stomach. He then takes 10 more pills a couple hours later with food. Those 10 pills are steroid based. The 19 pills he takes for 4 days in a row and then he doesn't for 24 days. This 28 day system will go on for 12 months. The only reason they would stop would be if they don't see it helping within a few months, he has serious reactions to the medication or it goes into remission. If it does go into remission, they cannot guarantee how long it would stay that way. The average is 2 years. Also, the idea that his heart will "heal" from this isn't really possible. They said it could, but the damage is done and the hope is to stop it from being damaged more.

Dad will go to Mayo each month and see the doctor. He will have blood work done weekly in Waterloo with results being sent to Mayo.

The one thing I should mention is that the doctor told us that if this would not have been found dad would have had heart failure in 3-6 months.

I would suggest you watch the video link below which explains it very well. If you have any questions, please let me know.

Please feel free to forward this email to others you feel would benefit from it.

Thanks for all the love, prayers and support.
Jamie

<http://www.bing.com/health/article.aspx?id=articles%2fmayo%2fac58df3860ff3cc34d9daa0a1db821ef.html&br=lv&q=amyloidosis> - some general overview info from mayo

<http://www.amyloidosisresearchfoundation.org/index.html> - a foundation with a web site with info

<http://www.amyloidosisresearchfoundation.org/video.htm> - this is a good video

2/1/10

Happy Monday everyone. Here is a little update on dad.

Bob and I and the boys went to see him yesterday. He was in a good mood. It was nice for the boys to finally get to see him. I noticed a weight loss from the last time I saw him a couple weeks ago - he said about 15-20 lbs. Jonny had made a "latch hook" design of a fish. Jonny gets pretty upset still thinking about Papa - he asks me things like "who will take me fishing if something happens to Papa". He and Papa are good buddies. Robby is hanging in there. He is seeing a counselor at school to help him. Robby worked on a charm "good luck" bracelet for dad that we gave him yesterday to keep by him and take to his appts. Robby is making 5 more, one for each grandchild. It is really cool - we found charms of a boat, an eagle, pirates, cross and then put the word "love" on it. Each grandkids will be just like it just with a different word.

Dad's brother, John, came to visit him on Saturday. He helped him do a few things around the house. Dad was very thankful for that. We all know dad can be pretty stubborn, but I have noticed a big increase in his willingness to have people help him. He knows he needs it.

His first follow up appt to Mayo is Wednesday, February 17. At that time he will have some lab work done and a CT scan of his lungs and liver. He then sees his doctor, Dr. Steven Zeldenrust later that day. I plan to go to Mayo with him this time since it is the first one.

I should mention this – sometimes dad isn't in a great place to talk to people, so please don't worry if you call and he doesn't answer. He calls back when he is feeling up to it. He does appreciate all the support, it is just overwhelming for him some days. And as for as visitors, please be sure and call ahead, again just to make sure he is up to it.

I think mom and dad are both a little bummed because usually at this time they would be in Florida. They have friends headed that way and I know mom and dad wish they were too. I just said, hopefully, next year the whole family can go together and celebrate dad doing better. J That is at least what I am praying for!

Finally, In case you were wondering what kind of Chemo/Meds he is taking for the 4 day cycle they are: Melthalan & Dexamethasone. I looked them up to see what kind of side effects might happen. One good thing is that the chances of him losing his hair seems like a small chance. The one side effect that is bothering him is that he can be easily confused and forget things.

If you want to read about these drugs, here are a couple sites:

Melthalan: <http://www.chemocare.com/BIO/melphalan.asp>

Dexamethasone:

<http://www.bing.com/health/article.aspx?id=articles%2fgoldstandard%2f6d8993bc7a8189696802d96fdc069446.html&br=lv&q=Dexamethasone>

Again, if you have any questions, please feel free to email or call me.

Thanks again for all the support!!! Jamie & Marty & our whole families!

2/18/10

Hi everyone, We made the trip to Rochester/Mayo on Tuesday night. We stayed at Marty and Dee's house and then went to dad's appointment at 8 am on Wednesday. The day consisted of the following:

- Blood Work
- Urine sample
- CT of lungs
- CT of liver
- Appt with his doctor

The following things are what they found/said

- Urine sample – ok and he shouldn't have to do again
- CT of liver and lungs did not show signs of Amyloid (this is a VERY good thing)
- Blood work – His glucose was slightly elevated and they want him to watch what he eats
- Blood work that he has done weekly in Waterloo and results sent to Mayo looked ok over the past month of his first chemo treatment.
- He will have blood taken weekly again in Waterloo with this next series of chemo

In the blood work they are looking for "light chains" in the blood. This is the protein that makes the Amyloid. A normal count for this is 2. When dad was seen at Mayo and diagnosed his count was 52. The idea of the chemo is to "kill" the bad protein and try and get his count down. Good news is that the blood

work yesterday showed his count at 34. This means the chemo did its job. So, the doctor is going to continue on the same path as we discussed initially.

Some other items of note:

- He does have some fluid around his lungs but this is directly related to his hearts ability to pump at a strong enough rate
- His heart enzymes are still slightly elevated, but this may not get better any time soon, if at all. Again the doctor mentioned that the goal right now is to stop any more Amyloid from forming. But only in about 50% of the cases do you actually see the heart getting any better.
- Dad still coughs a lot and again, that is just because of what is going on inside him. It may be awhile before that gets any better. (For anyone that calls him, know that he can't talk for very long sometimes as he gets coughing real bad)
- They gave him a medicated mouthwash to help with sores he gets in his mouth due to the medication

Again, I just want to thank everyone for their love, support and prayers. Some days are really tough has I think about what still lies ahead and the uncertainty of if this will all work for him. I stay positive for him, my mom and the boys, but to tell you the truth, as a daddy's girl it sometimes kills me to think about it. I know some day we will all lose our parents, so I have no clouded thoughts on that. There is still so much for my dad to do that I just continue to pray every day that he will get through this – prayer & faith has been a lifesaver for me. Being at Mayo really opens your eyes to what people have going on. We actually sat and talked to a girl before the CT scan that was in a wheelchair, one of her legs was gone from above the knee and she was bald and very frail looking. Her family was with her. You look at someone like that and realize that there are people worse off in this world and that you should be happy with any progress. So, again, thank you for everything.

All our best! Jamie (& Marty)

2/26/10

Hi everyone, Hope you had a good week. Thought I would send a short update out to you all.

Mom and Dad came over to Dubuque today and met me for lunch. Dad had called last night and said he was going crazy in the house and just needed out, so I "let him" come see me.

While he was here we went over some medical papers and got myself, Marty (& Dee) and mom signed on to be able to call and discuss his insurance with the insurance company. This will be very helpful as he get confused and frustrated with the insurance people quite a bit. I have been able to do a three-way call with him to help, but it will be nice to just be able to call for him.

Dad looked pretty good today. He moves slow as he gets winded very easy. His face is bloated, obviously from the chemo/steroid. And he also has some sores on his face and head that need to be looked at. Otherwise, he looks good.

The only really concerning thing is that his legs have gotten very swollen which is a side effect that we were told is a "call the doctor immediately" type of thing. They called Mayo and the doctor/nurse is going to call them back. I personally think that part of the issue is that he isn't resting enough. As example, on Wednesday I called and he sounded like he had just run a marathon. Well, no, he had taken the kitchen and bathroom sink pipes apart to clean/fix them. UGH. For those of you that know my dada, he just doesn't stop!

Thanks for all the prayers and support. He mentions all the cards and phone calls he gets and I know he really appreciates it. – as do I! God Bless! Jamie (and Marty)

3/26/10

Hi! I know it has been awhile since my last update but wanted to wait till he had another check up.

On Wednesday, dad had an appointment at Mayo to check his progress. Mom and Marty were with him. I felt bad it was the first one I missed.

Good news is that when they did the blood work and checked on the "light chains" in the blood. (Again, this is the protein that makes the Amyloid. A normal count for this is 2. When dad was seen at Mayo and diagnosed his count was 52 and when he had his check up last month it was at 34). At this checkup it was at a 27, so it is making progress.

The major concern and questions at this appointment really revolved around his coughing. As I have mentioned, he has been coughing so much it burst his eardrum and it even makes him throw up. Well, a couple weeks ago he was coughing so much that he actually bled out of his eyes!

When this happened they did call Mayo and worked through it with having him take cough syrup with codeine every 4 hours, plus they put him on a pain killer. The pain killer was suppose to help – not about killing pain – but that it numbs your nerve endings enough that it may help the blood vessels from popping and him bleeding. Ugh. The poor guy.

They have decided to do more though, because this coughing is really affecting his quality of life. So, on Monday, I will be taking dad back to Mayo so they can do some more tests. Specifically, they will be doing further xrays and doing a Bronchoscopy.

What is a Bronchoscopy? It is a medical procedure where a tube is inserted into the airways, usually through the nose or mouth. This allows the practitioner to examine inside a patient's airway for abnormalities such as foreign bodies, bleeding, tumors, or inflammation. The practitioner often takes samples from inside the lungs: biopsies, fluid (bronchoalveolar lavage), or endobronchial brushing. The practitioner may use either a rigid bronchoscope or flexible bronchoscope.

Just hoping the fact that dad was a heavy smoker much of his life hasn't done damage that is adding to this. Remember, the bladder cancer he was treated for in August/September, we were told that men that are smokers are at high risk for. Makes me think a little - any of you that are still smokers – QUIT!!!

Also, because of the tests on Monday he will not start his next round of chemo until that is over. Well, that is enough for today. I will send an update after next week's appointment. Thanks again for all the prayers!

4/14/10

So, I know it has been awhile since my last update, sorry!

Jonny and I went to Waterloo on Saturday night to spend some time with mom and dad. When I had talked to dad earlier that week I could tell he needed some time with me and the kids (Bob and Robby were in St Louis though). He was doing ok. Still a lot of coughing, which I will fill you in on in a couple minutes. Again, it continues to make it tough for him to talk to much. He looks like he has lost a little weight again. But he wasn't as sick this last time since they gave him medicine to help with that.

Let's see, where to start:

The Bronchoscopy – they did it and it came back "clear". They did take some samples that they were going to do some additional testing too, but we haven't heard on that yet.

The Coughing – At the last check up his doctor and the pulmonologist talked and decided to try dad on a breathing treatment to try and help with the cough. This consist of him getting a nebulizer (which is a device used to administer medication to people in the form of a mist inhaled into the lungs). The medicine that they are giving him is Lidocaine.

Breathing Treatment – We are hoping he will finally have all the components he will need to start this process tomorrow or Friday at the latest. He will do it twice a day. It doesn't take long to do the treatment

but he cannot eat two hours before or after he does it. And he cannot talk for 2 hours after. The medication numbs his throat.

Next check up at Mayo is Monday, April 26.

The question for the day is – how do you keep Jim Zahn down? Not very easy! He continues to have swollen legs and feet, BUT that is because he is doing too much some days! I am thankful for all the friends and family that have been helping him. He also has a wonderful neighbor, Richie Metcalf, that has been just excellent at helping dad - I am so grateful for him!

Oh my – the big news is that when I was in Waterloo we FINALLY got mom and dad a computer. Holy Moly – who would have thought they would actually finally get one! They don't have internet yet, but I did set them up with an email: ginjimzahn@yahoo.com. I will let you know when they are finally on-line. Right now dad is practicing his skills on the laptop playing solitaire. Hey, anything to keep him off his feet and occupied! ☐

Thanks again for all your prayer and help!
Jamie & Marty and family

5/3/10

Good afternoon everyone! Love that the sun is shining today! J

Well, quite a bit has happened since my last update, but I will try and make this brief by bulleting things:

- Dad is starting his next round of chemo today.
- He has been losing about a pound day, so the doctor is having him watch that closely
- The blood work from his last appointment shows that the light chain count is down to 19. (Again, this is the protein that makes the Amyloid. A normal count for this is 2. When dad was seen at Mayo and diagnosed his count was 52, it then went down to 34, last appointment was 27, so it is making progress).
- Dad was in the hospital for a few days the other week due to his legs being very swollen. They estimated he had around 9 lbs of fluid in them. He had to stay long enough for it to get under control and got out in time for his appt at Mayo.
- Remember that the Amyloid affects his heart, so he has to be VERY careful about what he is doing as far as activity and eating.
- During his hospital stay, dad decided he really wants a cardiologist in Waterloo that he can see if needed
- At the appt in Mayo, the doctor agreed that he should have one. Dad will be seeing Dr. Jabber (spelling?) this month. I plan to go to that initial appointment. The good thing is that this is the cardiologist that helped me get dad out of Allen Hospital a few months ago when the other doctor wouldn't release him to go to his Mayo appt. Dr. Jabber also spent some time at Mayo, so he is a good person to have working with them.
- Since dad isn't approved by insurance to see a cardiologist at Mayo this is the best option for now.
- FINALLY – all the items dad needed to start the breathing treatments made it to him. He has been doing it for a little over a week now. He says it seems to be helping so far.

Thanks again for all the thoughts and prayers! Jamie & Marty (and families)

Be of good courage, and he shall strengthen your heart, all ye that hope in the Lord. - Psalm 31:24

5/12/10

Good afternoon,

I write this email as I sit in dad's room at Allen Hospital. Dad came in yesterday morning after he dropped 10 lbs over night. The ER did an x-ray and thought he might have pneumonia. They ordered CT scans of

his pelvic, stomach and lung areas. We found just a few minutes ago that the scans showed up clear and that whatever the ER doctors saw to think he had pneumonia was wrong... go figure with this place.

They did an echocardiogram this morning and now we are awaiting on the cardiologist to come in and let us know how that turned out. They are also sending in some people to talk to us about his congestive heart failure. Obviously, this just all comes back to what the Amyloidosis is doing to his body, specifically the damage that is happening to his heart. His cough is also still pretty bad.

They are changing some of his medications. They think that is what is causing the drastic weight loss. It has a lot to do with the fluids in his body. I am usually pretty leery when they talk about changing things, but the cardiologist was here last night and he understands dad's Amyloidosis. Actually this is the cardiologist that helped get dad out of here back a few months to get him to Mayo.

I talked to dad's doctor at Mayo yesterday. He is great and helped me understand it all too. The doctor here knows that Mayo is just a call away for anything.

And finally the other thing that has them concerned right now is that his blood pressure is dangerously low, so they are hoping the change in medications will help that. They won't let him go home until it is better. It causes his energy level to be very low, so he gets dizzy.

Just had a few visitors: Curly and Wilma (they helped raise my dad and are the "parents he never had", so it is great that they stopped), Frank (my dad's brother) and family friends Bob and Jackie Kresser. I so grateful for all the support the family receives.

Dad is dozing off, so I just sit here on the computer - thank goodness for free wifi at the hospital and my son's laptop! :)

So, keep on praying and I will continue to keep you posted! All my best!
Jamie & Marty (and our families)

6/8/10

Hi everyone,

Well, we have been pretty busy since the last update. The biggest news is that Celine (my oldest niece) graduated from high school last weekend. It was a great moment! I cannot believe she is that old! I am very excited too because she is coming to Clarke next year! YEAH!!! Dad did pretty good at the graduation. His legs got swollen sitting in a folding chair that long, but once he was able to get them up and rest that night, he was much better the next day.

Dad has his next appointment at Mayo on June 15th. I plan to go with them again. They are going to do the regular stuff and meet with his doctor, but are also going to do some more heart tests and see how it is doing.

I have been doing a lot of research on Amyloidosis (AMY) again. And I have reached out to others affected by this disease through the Support Groups - www.amyloidosisupport.com . I talked to dad this past weekend. I found out that the nearest support group meets in Chicago at the end of this month. I would like him to go it with me. I think it would be good for him to meet others that can understand what he is going through – he agreed! The people I have met over the web have been AWESOME. It is a god send!!!

Dee has been doing some research on some procedures for the heart. One is very interesting. She understands all that stuff and I think it is great!!!

As always, thanks for all the prayers.
Jamie and Marty – and our families

6/16/10

Well, we took another trip to Mayo yesterday. Lots to update you all on. I have added some new friends and family to this list, so thanks for your interest in knowing what is going on with my dad and for all your support and prayers.

- Dad is starting his next round of chemo today. Remember it is 4 days on and 24 days off.
- His weight has been steady at about 150, so that is good. They don't want him to fluctuate more than 3 lbs within a day or so, so he continues to weigh himself every day. He can change his dosage of Lasix as needed to stay on top of it.
- The blood work showed that the light chain count is down to 10!!! (Again, this is the protein that makes the amyloid. A normal count for this is 2. When dad was seen at Mayo and diagnosed his count was 52, it then went down to 34, last appointment was 27, then it was 19, so it is making progress). This is great news as it means the chemo treatment is working to get that under control. Hoping it will be close to normal by his next appt.
- Remember though that until this is under control the amyloid is still having a negative effect on his heart.
- Dad had a new ECHO done and the results of that showed that his heart has been "hurt" more by the amyloid as it is pumping even less/harder than before.
- You may recall that dad has started to see a cardiologist in Waterloo (Dr. Jaber) last month. Which dad does like him.
- Although I am happy to say that dad agreed to get a "second opinion" from the cardiologists at Mayo.
- Marty and I felt this was EXTREMELY important since those are the guys that truly understand what Amyloidosis is. They are the ones doing research on it and can really tell if dad would ever be a candidate for something to help his heart.
- The one bad thing is that dad is still very fatigued and gets winded easily. Also, the coughing hasn't gotten any better.
- For the coughing, they are going to have him see the pulmonologist at Mayo as soon as possible. Thank goodness.
- They are also keeping track of his kidney function as they can be negatively impacted by this, but so far so good!
- We also discussed his diet. He needs to get more calories in him to build back up his body. They "prescribed" a dairy queen a day! ☐
- They also encouraged him to continue to cut the salt intake out of his diet and take in plenty of protein
- And they also said he should eat all day – a little at a time. This will help given that he doesn't have a big appetite

Overall it was a good visit. We were able to have lunch with my dad's brother, Walt. And Marty was able to leave work to be at the appt with the doctor.

Thanks, Jamie

7/7/10

Hi everyone! Well dad had an appt on Tuesday at Mayo. This was a last minute day - as I mentioned last time - they were going to try and get dad in as soon as possible to see the pulmonologist and cardiologist. Marty, Dee and mom had to work, so I went with him. I know dad gets nervous about these appts, so I am glad my work was flexible in letting me go with last minute notice.

Well, the day consisted of: Lab work, xray, mtg with cardiologist, mtg with pulmonologist, pulmonary function test, echocardiogram, electrocardiogram.

The tests all went ok as a whole. Dad gets really nervous about the echo and electro because they have to put the sticky things on his chest. Given how fragile dad's skin is, when they take those off, it will actually tear his skin off. Thankfully they did a better job this time and he should only bruise a little from it.

For anyone that hasn't seen dad in awhile, I should explain the fragile skin. Dad bruises very easy and if he barely rubs them, it can tear the skin back. It is very sore and he has to be careful. Actually, when he was showering on Friday, when he rubbed his washcloth over his waist area, he tore a very large piece of skin off. He had to figure out a way to get it to stop. We were thankful that the nurse at the cardiologist's office gave dad a way to protect the sore and hopefully help it heal. It is in such a bad spot given the way his pants fall on his waist. The doctor did explain that steroids can weaken the skin, so between that and dad's weight loss you can understand why it is happening.

The main reason to see the pulmonologist was to see if he had any more ideas in how to help dad get the cough under control. Actually, the doctor is at the end of his ideas. So, this last thing he is trying is to prescribe dad a low dose (10 mg) of oxycodone (oxycontin) - yes - the narcotic. He is to take one twice a day (about every 12 hours). He prescribed him enough for a couple weeks. If that doesn't help then the doctor is going to have another person also look at him. I can tell the doctor just doesn't know what else to do. Very frustrating, but at least they are trying something else for now.

The time we spent with the cardiologist was really good. I was very impressed with him (and so was dad). He is a cardiologist that specializes in transplant and congestive heart failure. He reviewed all of dad's notes and just talked very openly about the reality of cardiac amyloidosis. There really is no history of the heart ever recovering from the damage done by the amyloid. He confirmed that dad has a significant decrease in heart function. He said that dad's heart basically pumps about half as well as a normal heart does. This is due to the thickening of the heart. Just to clarify, dad's heart isn't "growing" larger, instead it is "thickened" with the amyloid (protein).

The cardiologist did mention there is one medication that he can try to help with heart function, but there is no proof that it will help and the side effect is coughing, so obviously we can't try that right now.

I did ask about options for dad. Transplant is not an option at all. I mentioned to him something Dee had found info on called a lvad:

<http://www.mayoclinic.org/heart-transplant/vad.html>

<http://www.webmd.com/video/heart-repair-study>

<http://www.youtube.com/watch?v=DLV6kIfvSDA>

Actually the doctor said that this was in the back of his mind too. That there has been a few cardiac amyloidosis patients that have had it done and he has worked with the surgeons on it. We didn't talk in detail, but the doctor would like to continue to see dad and assess how it is going to then make recommendations on what we could do. That was the best thing I had heard all day.

His next appt is on July 28. He will be having blood tests and xrays as well as seeing Dr Zeldenrust (Hematologist), Dr Schirger (Cardiologist) and Dr Krowka (pulmonologist). Keep him in your prayers. Hoping for a good report on the amyloid count. :)

By the way, this past weekend at the river was a good weekend for dad. He was able to put the boat in and even though it rained it was still a fun time with family and friends. I know a lot of people gave him "well wishes" before they left knowing he had this appt and even though my dad doesn't always say it - he really does appreciate it. It feels good to know others care.

It was nice to have a few hours with just dad. We talked a lot on the ride home about family, his childhood and all the good/bad that happened along the way. Who would have figured that "trouble maker of a kid" that had a choice of jail or going to the Navy would turn out to be such a good friend, brother, dad, husband, etc.. Oh yes, I know he isn't perfect by any means, but he is a good guy and I cherish all the time I have with my dad.

Please know that although many of you thank me for these update emails, I need to thank all of you for being such a great support to me and my dad (and our whole family). Keep the prayers coming.

All my best - Jamie (and our entire family)

9/14/10

This update was meant to tell you about last weeks trip to Mayo, but I am actually sitting in the hospital with dad right now.

Mom brought dad in at about 2:30 am (this morning). Dad couldn't catch his breath and was afraid to fall asleep that he may not wake up. He spent a few hours in the ER and then was taken to the ICU. He was just a little bit ago brought to the cardiac tower at Allen in room 381.

While in the ICU they did an EKG and we are still waiting for them to do an ECHO. They have placed a "pic" in him. This is something that stays in him (similiar to a port that is placed in a patient for chemo). This will help them when he needs an IV. His skin is very blotched and he has been bleeding on his arms from all the pokes. He looks pretty rough.

After the tests his cardiologist will touch base with us. They plan to keep him for 2-3 days. Basically, it is his heart failure from the Amyloidosis. He was lucky to have come in or it could have been fatal.

Some new developments is that his Liver and Kidney enzyemes are off, which could mean that the Amyloid is now affecting those organs. They would have to biopsy them to know for sure, but they are watching it right now and haven't ordered anything specific for it.

The one thing that made me "upset" is that the nurse read from the notes from the cardiologist here that basically he "he is in heart failure with no hopeful plan to help".

He is down to 136 lbs today. He was at 139 last week at Mayo. The news from Mayo is that the chemo and steroid continues to make some progress on the Amyloidosis but his heart continues to lose more function. Our next appt next month we will see the cardiologist again.

To be honest, it is really scary. Looking at him now sitting here, he just isn't in good shape. Tough to watch someone you love go through this.

The highlight of the past couple weeks was that Jonny learned to ski and on the last day of "on the river" my dad was able to drive the boat when he skied. Jonny was so happy to have Papa Jim pulling him and I think it was a big moment for my dad too. Thanks to everyone that helped teach Jonny for them to have that moment.

Thanks again for all the prayer and support. I can't say thank enough. I would ask that you pray for the many people we know right now going through health problems.

Take Care! Love! Jamie

9/20/10 (evening of 9/19/10)

Hi all! Well, it has been an extremely BAD day. Let me explain how we got here.

After dad was released last week from the hospital, I called the Mayo Clinic to see if they felt he should be seen by them given what the doctors said at Allen. Mayo was extremely concerned and felt it was necessary to see him asap. So, we scheduled an appt for some lab work and for him to see the cardiologist on Monday.

So, I came to waterloo today at 4 pm and met mom and dad to start the "oh so familiar" trek back to Rochester tonight since his first appt was for 7 am tomorrow.

The trip was cut short. (for those of you from waterloo, i will explain where we were at).

Mom was driving and I was in the passenger seat. Dad was in the back behind mom. We were on Elk Run Road heading towards Dunkerton Road to get to the highway. We didn't get that far. While driving on Elk RuN Road, we were about at the Tyson meat place and dad started getting hot so I was trying to help him get his coat off. A couple minutes after he started to cough. But a really strange cough. And he wouldn't answer us. He couldn't talk. Mom pulled over and I was wiping saliva from his chin. I came around the side of the van because I thought he was going to throw up. When I got there his eyes were rolling back and he was starting to convulse. I told mom to head to Allen Hospital immediately. I tried to hold on to him as we drove as his right side of his body wasn't moving and he was erratic. We got to the ER at Allen and I ran in for someone to come help us. Finally a nurse saw and ran out. He almost dropped dad getting him out of the van and I helped lift him. His whole right side was "stiff". They rushed him back. It was so scary.

In a nutshell, he has had a stroke. It was horrible to watch. I had to make the decision on how to treat him. It was so hard. Thank goodness I was able to talk to Marty and Dee by phone to help through it. I can honestly say I didn't think he was going to make it. We were VERY lucky to have been so close to the hospital that they could start medication within a good amount of time. They say the first hour within a stroke is most critical. Oh, it was bad.

He is in the ICU tonight. They are glad that he is getting function back in his body, but he is very confused. Not sure where he is and how he got there. He didn't recognize us. By the time we left tonight he was catching on more. He is very frustrated, like he knows what he wants to say but can't say it.

Marty, Dee and the girls and bob and the boys all got here and saw him, Very hard on the kids. Hard for them to see papa like that - especially when he couldn't remember their names. He first called Robby his son and then when Jonny was right by him he asked where Jonny was. It is like he knew names but couldn't put them with faces or vice versa. Thankfully when we left tonight he got some right. He was able to look at me and say who I was. He knew tom was his friend and he looked at amber and knew her.

We are planning to try and get a transfer to mayo tomorrow. We will be on the phones early working on it, so I will keep you posted.

Please keep the prayers coming. We need it. Thanks for Tom and Sally for being with us today. It was good to have some extra shoulders to cry on.

Well, it is 1am and I need some sleep. But first I need to thank god for one more day with my dad and grateful for it happening so close to hospital. I really wish I knew what gods plan was for my dad and our family. But since I don't, please, everyone, just say an extra prayer for us.

All my love, Jamie and family

9/20/10 (morning)

FYI... Dad is having an MRI and a scan of his neck (the caratod? veins). I called Mayo at 8:01 am this morning and they are working on a transfer. Basically, as soon as the tests are done here and the doctors are ok with the transport they will get it done. The ICU doctor here and the ER doctor at Mayo will facilitate it. Once at Mayo/St Marys, they will assess him to decide where to be fully admitted, i.e. cardiology, neurology. Dr Zeldenrust's nurse is who is helping me, so he is involved. Just wanted to let you know where we are at as of this morning. Peace and Prayers, Jamie

9/20/10 (evening)

Well, we are here - Mayo Clinic/St Mary's Hospital. It wasn't as easy as we thought to get him transported but right now that doesn't matter because he is here!

The neurologist in Waterloo said the mri and scans showed no more bleeding. The stroke did come from the heart - obviously due to his amyloidosis. He has a scar on his brain where the stroke occurred. It is in an area that affects the right side and speech. It was a massive stroke. Thank goodness the medication worked. The neurologist recommended dad going on a blood thinner which is very concerning due to his

AMY. Basically, we (Marty and I) said that nothing is to be done with him without mayo involvement. So, after many calls with mayo we got the transfer.

As a side note, it was interesting that I was in the nurses' station on the phone with mayo with the nurse having me do much of the explaining. When I got a medical degree, I don't know! :)

So, when we got here the cardiologist came and saw him and verified that a blood thinner is very concerning and they don't necessarily agree. So tomorrow dad is getting two types of echocardiograms done as well as being seen by the neurologist here. They are reviewing everything before making a plan. This is a very thorough place. The stroke may now make the option for an Lvad not possible, but they are going to do all the tests they need to make a plan for him.

So, they gave dad something to help him sleep, but they also gave him lasix to help with fluid which means he is going potty alot. So hopefully he gets some rest tonight as tomorrow is a big day of tests.

As always, thanks for prayers, as we know more, I will let you know. Just know he is in good hands now.

We are enjoying watching football together and sitting here being able to have a conversation with him tonight is such a good feeling - I love my daddy! So keep the prayers going that they can help him.

All my best – Jamie

9/21/10

Long day at Mayo/St Marys. It consisted of:

- Neurology: Two doctors saw dad. Did multiple tests to check the after affects of the stroke. Allen hospital didn't send the MRI and CT Scan they did so they had to overnight them to arrive here tomorrow. So, they need those to see what else that may need to do. Focus on how to prevent another one which as I mentioned before is an issue due to his bleeding.

- Dr Lin (a doctor specializing in Heart Failure): Was here multiple times. She explained that once all the doctors see dad and come up with what they would like to do, then they will all conference with each other to come up with the plan.

- Lvad Team Doctor: Came in and did an exam and discussed the Lvad option with us. With the stroke and dad's bleeding issues this option may not be viable any more, but they are still keeping the door open. This is a MAJOR surgery and commitment of dad and family, so it cannot be gone into lightly.

- ECHO: They did two types of echos today. The good news is that the one did not show as much "more damage" as originally thought. The one that looks at the back of the heart did show a small hole in his heart. Not something they want to consider surgery on given dad's current health.

- Dr Schirger (cardiologist): still needs to see dad

- Dr Zeldenrust (hematologist): is aware of all that is happening and he will be brought in when they do the "conference" to help solidify the plan.

- Lvad info: <http://www.mayoclinic.com/health/lvad/MY01077/rss=1>

- After affects of the stroke are interesting. One example when dad finally got to order a meal today he tried to write out what he wanted while looking at the menu. He wrote cottage cheese. But "cheese" was spelled "street".

Been a busy but good day. We feel so relieved to have him here. They are amazing.

Thanks again for all the prayer and support.

9/23/10

I am back in Dubuque. Very tough to leave dad yesterday afternoon and the 3 hour drive home alone is too much time to spend alone thinking about EVERYTHING!

But here we are today! Good news is that the files from Allen finally got to Mayo late yesterday and nothing on them showed the neurologists anything that is going to change the plan that they are working on for dad.

Physical Therapy saw dad yesterday and are very happy with function of his right side. This means he will not have to do an inpatient therapy – he can do outpatient. There is still going to need to be something for the memory/speech, but we are not sure what yet. He struggles a lot with the memory and gets frustrated. Honestly, as I thought about that on the way home, I think what is really tough for him is that this awful Amyloidosis has taken such a toll on his body, but he still had his mind. Now you add this to it and his mind is struggling – that makes it hard on him. He got emotional trying to talk to a couple people yesterday on the phone and had to hand the phone to me or Marty to finish talking to them. So, if you talk to dad just be understanding to that frustration for him.

The cardiologist was going to talk to the heart surgeon today regarding the Lvad. Even though they haven't ruled dad out as a candidate, it would seem that the opportunity to have it done is farther away than hoped due to all this.

The cardiologist is also against the idea of dad being on Coumadin due to the bleeding concern. It sounds like they will treat him with a high dose of aspirin. It isn't as good of a treatment, but it is safer. I know I keep talking about the bleeding. I have attached a couple photos of dad that I took yesterday (I document everything). You can see his bruising issue and the skin tears he gets from it. Sorry, they are a little graphic, but I know some of you haven't seen him and this helps put it into perspective.



So, right now, we are really waiting for all the doctors to “conference” and make the final assessment and plan. If all goes well, he could leave Mayo today – tomorrow at the latest.

I want to thank everyone for their prayers and support. Although he isn't “out of the woods”, he is doing better. Most of the doctors and nurses have plan and simply stated it is a miracle he is alive and doing as good as he is. Thank goodness we were able to get him to the hospital as quick as we were or that would not have been the case!

I know some of you are new to this email list, so I am attaching some links for you to read about what dad has to help you understand.

I will let you know when he gets out and the final plan is. Thanks again! Jamie, Marty and our families!

- What is amyloidosis: <http://www.mayoclinic.com/health/amyloidosis/DS00431> (Dad has Primary AL Amyloidosis with Cardiac involvement)
- On-line support group: <http://www.amyloidosissupport.com/index.html>
- What is an Lvad: <http://www.mayoclinic.com/health/lvad/MY01077/rss=1>

9/24/10

The good news is that he is out of Mayo/St Marys and heading back to Waterloo with mom as I type this!!!

He didn't leave yesterday due to a few items. One was that his right leg had swollen so they wanted to do an ultrasound of that and make sure there was any clot (and there wasn't). They also started him on the aspirin and wanted to make sure he handled that ok. Plus a couple more doctors wanted to see and talk to him.

I don't have a ton of details yet from mom, but she is going to call me tonight and fill me in. What I do know is that he has a lot of follow up appointments, especially when he goes back to Mayo next month. He will continue the chemo treatment with now close attention to these new issues.

Dr. Joyce (the heart surgeon) saw dad yesterday which was nice. He definitely wants dad to continue his chemo with the hope that someday the Lvad could be in his future.

Dr. Lin (the cardiologist) is going to now be a regular doctor that dad sees. We really like her, so this is great! She mentioned something that could be a possibility for dad. I am not sure I mentioned this previously, but on top of all of this dad has continued to have a irregular heartbeat. She mentioned the bottom part of the heart is what is concerning her. The top part does too, but now with a stroke it doesn't surprise here on how it is acting. So, she mentioned something similar to a pacemaker could be an option to help. Because of the irregular heartbeat coming from the heart not "firing" like it should (this has to do with the electrical pathways in the heart) the reality is that dad could have a Sudden Cardiac Death from it. I did some checking on the internet and found some of this info helpful <http://www.americanheart.org/presenter.jhtml?identifier=4741> and http://www.medicinenet.com/sudden_cardiac_death/article.htm . Just another thing to keep an eye on.

No matter what the doctors have all found and even though it seems scary and overwhelming, I am just happy that we are able to have the conversation given that dad is still alive (even though he isn't doing much kicking!) and we get to work with such awesome doctors as there are at the Mayo Clinic! No matter what happens I know that we are going to be honestly able to say we tried it all!

One final note for now, if you talk to dad, again, just keep in mind that his ability to remember and then to put his thoughts into speech is very tough still and he gets frustrated, so don't be upset if he isn't much of a talker right now. J

I will keep you posted. The support has been great. Thanks to all. Jamie (and Marty and families)

9/27/10

Can you believe it has been a week since dad's stroke. This really did feel like the longest week of my life!

This update is short and sweet just to say thanks to everyone for all the prayers and support. I met dad and mom at the cabin yesterday and Robby helped Uncle John (this is my dad's youngest brother) pick up things and get ready for winter (and a possible flood). Then our friend, Doug helped John winterize the cabin this morning before they headed home. And Tom, another friend, helped bring some things back home for him. Everyone at the river – "our other family" – has been so great around there helping.

Dad is doing as good as he can at this time, still a long road ahead. The speech is driving him crazy – he stutters as he tries to express himself. I just smile, because if you would have asked me a week ago if I was still going to be able to communicate with my dad, my answer would have been a lot different. We can live with this.

<http://www.youtube.com/watch?v=PGvje7x9Oto> – This is a video Mayo gave us to watch regarding the Lvad. Very interesting. We are so hopeful that this might be a possibility for dad some day.

Have a great week! Jamie

10/10/10

Hi everyone,

I wanted to fill you in on what has happened over the past week and a half. Dad noticed quite a bit of blood in his urine. We went to the emergency room a week ago in Waterloo (mom and marty were with him). They thought it was a broken blood vessel. He went to his family doctor and he said to "watch it" and drink plenty of water and again said the same thing. Did seem overly concerned about it - go figure!

When it didn't clear up, he called the Urologist (in Cedar Rapids) and they had an appt on Friday. The doctor immediately sent him to Mercy Hospital (Cedar Rapids) to have a procedure done. They had to surgically remove a large blood clot from his bladder. They kept him over Friday night to watch it.

Jonny and I went down yesterday to see him. He kept passing "smaller" clots throughout the day. This is very painful for dad. They kept him over last night again. I asked dad to have the doctor call me when he saw him today.

The doctor called me about 10:15 this morning. They are 50/50 on whether he will stay again tonight. One minute it seems like they are getting better and then he gets up and walks around and the next thing you know, he passes more.

They have taken him off the aspirin to try and help with the bleeding. Of course, this makes me nervous because he's on that to prevent another stroke.

The doctor in Cedar Rapids isn't sure if this has to do with the Amyloidosis but assumes it is. I would suspect the same. I plan to talk to Mayo tomorrow about it.

The doctor did say that dad will probably go home with the catheter for a few days. That will make dad real happy! :)

Right now the catheter has two jobs. There is one tube sending him a saline solution to help "clean out" the clots and there is another tube that carries it out. Not fun for dad at all. I am sure all you guys can understand that!

I will keep you posted. Please keep all the prayers coming! Jamie

10/22/10

Good morning. Well, I hope all of you had a better night than I did - or should I say that dad did.

On Monday, I called Mayo since dad's legs were very swollen and getting worse. Dr Lin said to up the medication and see how he was in a couple days. On Wednesday, dad/mom called her and explained it was no better. Dr Lin wanted him to come in asap, so they had an appt yesterday for blood work and to see her. When they saw her, she immediately admitted him to the hospital.

I came up last night. Marty was able to be at the appt, so that was good. I am not sure where to start on what is going wrong right now.

First he continues to have blood in his urine and passes blood clots. Urology will be coming in again today to follow up on that. Right now (I am sorry to be this blunt) but the catheter looks like it is passing more blood than urine.

Second, his legs are extremely swollen all the way up. They are hard and heavy. He has them wrapped and they have him on an IV medication to try and get them down.

Next, he doesn't sleep and the medication they put him on really messes with him. Between the pain pill and sleeping pill you would have thought that he would have slept great last night. Heck no! He continually tries to stand up and they don't want him to. He is confused and doesn't know where he is. He

kept trying to take out his catheter and even unhooked himself from the heart monitor he is on. The nurses were in the room every hour trying to settle him down. They put an alarm on his bed so they would know when he was getting up.

The last thing is that his irregular heart is still a major issue. Dr Lin is watching it close to try and see if it is worse because of what else is going on right now, i.e. the swollen legs. I just know that every time he gets up, they come in to tell him to lay back down because his heart starts doing "funny things".

Each time he lays down I think he will fall asleep but it only lasts about 10 minutes and then he is trying to get up or mess with his monitors, etc. It really is like having a little kid to look after. It is very sad to see my dad like this. The strong independent guy he was just a year ago really is gone.

So, it was a long night, not sure what to expect from today yet. Will be anxious to talk to the doctors today about all of this.

Btw, dad was supposed to have his next appt here at Mayo next week to start his next round of chemo. That is now up in the air based on all of this.

I will keep you posted. Thanks again for all the prayers and support. Jamie and Marty and families

10/23/10

Good afternoon everyone. Sorry I didn't send another update sooner. Yesterday was crazy with all the people coming to see dad. And I was pooped last night after not sleeping much the night before. I am sitting her now watching the Iowa State game with dad, waiting for the Iowa game to start. He keeps dosing off, but that is ok. :)

The best way to explain yesterday might be to just list how saw him and why:

- Dr. Miller is the consultant on staff. He comes in with his entourage of nurses. He has come in each day and just updated us on what is going on. The main thing today is that they are taking him off the IV Lasix. This morning his legs are finally looking better - YEAH! They don't like to keep him on the IV as it starts affecting the kidneys. So, they just stopped the Lasix and are going to start him back on a oral medication for it.
- Sister Eileen: a sweet lady that came in to talk to us about mass and having Eucharist. She has a great Irish accent. I could have talked to her for hours. She told me, "we are on the same page, I can tell".
- A priest came in later and did a prayer over dad and actually did the "Anointing of the sick".
- Social Worker. She came in to talk about home care. After conversations from everything from hospice and home care to nursing homes, we came to the conclusion that we need to look at home care, i.e., someone that could come in every other day or so and check in on dad. This would allow for mom and dad to ask questions and have someone to turn to instead of just going to Allen Hospital ER all the time. All that Allen does is somewhat "patch" him up and send him home. Since dad is still planning to be on chemo, Hospice isn't an option yet.
- The Social Worker is going to have her coworker, Shirley, come and talk to mom and dad on Monday
- Urology (multiple doctors and techs) - They continue to monitor the bleeding. He is still having it. They would like to run a few different tests to see what is going on in the bladder. Items they are looking for would be the bladder cancer, prostate cancer, or if the Amyloid is now in the bladder. One of the tests would mean putting dad under anesthesia. They do not want to do that yet given his heart and his blood pressure. They don't know if his body would handle it. So, in the mean time they are going to try and do a scan.
- Dr Lin came in last night. She is going to talk to Dr Zeldenrust to figure what the next steps will be for the Amyloidosis. Not sure if he will be able to start his next round of chemo until they have this other stuff figured out. Basically, although there are all these separate items going on what dad they do all interrelate.
- Occupational Therapy - came and talked a lot about their house and dad's ability to get around. It was good that dad's friend Tom has helped put some grab rails in the bathroom, etc. to help. They asked lots of questions and will make some recommendations for mom and dad before they leave.

- Physical Therapy - came in yesterday and did an assessment. They came back today and did some exercises with him. They even took him for a walk with his cane. He did really well! :) They will continue to work with him while he is here.

- And then there is a team of nurses that are helping us with the "quality of life" topic. Helping dad and the family make plans and talk about what is the best for dad. These ladies are great. They spent a lot of time with us and I really appreciated it. I think it helps put this in perspective. They will continue to be a resource while he is here.

I think the big thing for me is that this time when dad is finally able to leave (we have no idea when that will be), that there will be a plan for dad that will also help mom as his primary caregiver. :)

All of dad's brothers were able to see him yesterday (Frank, John and Walk and Sharon). It was nice to have them around. Walt and Sharon brought him a piece of pie which always brings a smile to his face.

Well, enough for now. I just ordered dad lunch, so it should be here soon.

Again - THANKS so much for everything. All the prayers and support are so appreciated!
Jamie (and Marty and families)

10/25/10

Just a quick update today. I came back from Rochester late last night. Was tough to leave him while he was still there.

They finally took the catheter out, so that was a relief to dad. He still had some slight blood in the urine but it is clearing up. They are still planning for an ultrasound. Then once his kidneys are a little better they can try the other test. More than likely they are not going to be able to put him under (fear his heart won't take it), so they will have to just go in and "take a snip" of the bladder without it. OUCH. But that way they can do the biopsy and see if the Amyloidosis is in the bladder.

They are waiting on the cardiologist and hematologist to talk and see what the game plan is for this week. I will keep you posted.

Dad has some visitors over the weekend. He enjoyed it, even though he would doze off on them sometimes! And lots of pie was brought to him too!!!

All my best! Jamie

10/26/10

Hi everyone, Well the good news is that dad is home! J

They did the ultrasound of the bladder and that came back ok, so the next step is the other test and biopsy. They will do that at an appt they are setting up.

Since the swelling in his legs were finally down and they had done all the tests on his bladder that they could at this point, they felt it was safe to send him home.

They are scheduling his appts with cardiology, hematology and urology as well as tests for next week sometime. Hopefully more answers to come with that. And to clarify, that means he is not starting his next round of chemo yet.

So, it was a tough 5 days, but he made it through. Still a bumpy road ahead, so continued prayers and support are appreciated.

Thanks so much! Jamie

10/30/10 1:50 pm

Well, we are at Allen Hospital. Mom called me this morning that dad was in pain and confused. He also had the chills and couldn't move very good. Celine was at their house, so she called the ambulance to come get him. I called Dr. Lin at Mayo and she said to have him come to Allen and contact her later.

They believe it is an infection. But they don't know where it is in his body. The ER doctor asked mom and I about his "wishes". At this point they are saying it is 50/50 (maybe even worse) he will get thru this given his overall issues. I have asked the doctor here to talk to Dr Lin, so we are arranging that. Marty is on his way here too.

I just have a few minutes now as they are settling him into the ICU. I will email when I know more. Send prayers please, we need them right now. Dad is in a lot of pain and really not good. Hard to hold his hand and tell him it will be ok.

THANKS, Jamie

10/30/10 (evening)

Some of you may have heard, but my dad passed away tonight. Thanks for all your love and support over the past year.

"Isaiah 40:31 - But they that wait upon the Lord, they shall mount up on wings as eagles; they shall run and not be weary, they shall walk and not faint".

To all that might read this:

- **Love your family when they are here and don't ever give up hope – I didn't**
- **Fight for what is right! I had to fight with a lot of people through this. From insurance companies to doctors – but I would do it all again**
- **Keep making AMY a priority. Awareness is key! And be sure you are educating yourself!**

Me and my dad at my vow renewal at my parents place in Prairie Du Chein on 8/14/10. My husband and I were going to do this next year (which would have been 15 yr anniversary) but due to my dad's sickness we did it this year! I am SO glad I did. I love and miss my dad so much!



The hardest thing of leaving my dad the night he passed. After everyone had their chance to say good bye I was the last one to go in a final time. I had held his hand so much over the past year that the reality that I would never hold his hand again was too much to bear. I took this photo to always remember it.

