



Welcome to the Renal Diet Headquarters podcast with your host Mathea Ford, CEO of Renal Diet Headquarters. This our weekly talk about how you can succeed with a kidney diet, brought to you by renaldietHQ.com a website whose mission is to be the most valued resource on kidney disease that people can use to improve their health.

This week we are talking about kidney support groups and how they can affect a patient and help them or allow them to grow in our knowledge about their kidney disease.

This episode is being published on January 29, 2014, and you can find the information in the links I talk about in this episode at renaldietHQ.com/006 on our website. You can also find us in iTunes and on Stitcher radio. I will put the link in the show notes, and show notes are just our blog post, if you go to renaldietHQ.com/006 that's where you would go to find the written out version of some of the things that I talk about so that they easy for you to find. So I will put the link in the show notes about iTunes and Stitcher radio for you to subscribe. Any comments would be appreciated and you can send them to podcast@renaldietHQ.com.

Okay, so I wanted to first take a moment and talk about what I'm working on. I am working on several different things and I want you to be ready for those and if you can provide some feedback, I am going to ask you to give me a little bit of feedback. So, I'm working on, it is called a CCD diet book, and it's about being a diabetic and carbohydrate controlled diet, that's what CCD means. I'm finishing up that book and I actually hope to have it released before the next episode. I will be putting that out on Amazon and next week I'll probably give you a link to it, but it's about being a diabetic, so it's not all the way to kidney disease, but it's helping you control your diabetes. I'm still working on my breakfast dialysis cookbook and if you, oh, I forgot to tell you, with the CCD diet book if you want a discounted price, if you email me by February 5, 2014, at podcast@RenalDietHQ.com and just say "send me the link and the discount for the CCD diet book" then I will send you a link and a discount code to use to get some money off and it'll be cheaper than you can get on Amazon. So just for a short period of time I will do that for you if you get me a note by February 5.

Also, I'm working on a large package about kidney disease with many workbooks, videos, and audio. It is going to have some meal planning information and it is going to

have information about videos, about how to read menus in restaurants, and all that type of stuff. It's going to be pretty extensive when it comes out, I will have a specific list of all the items that are in it, but I also like to hear from you, if you wouldn't, mind to send me a note, and tell me what you want to learn more about for kidney disease. This is the part where I said I need your feedback and I want to know what you're looking for in kidney disease which you want to learn more about. It is going to be a large package, but if there's something special that you feel like is really important or that you have looked for long time you can't find, let me know. You can let me know by emailing me again at podcast@RenalDietHQ.com Tell me "Hey, I would like to know this about kidney disease".

So, I also want to talk for a minute, I got interesting connection today on LinkedIn. A lady named Gail Rae, she sent me a connection and I accepted, and she sent me a note and said a blogged about your book on my blog. She blogs about kidney disease and chronic kidney disease, like I do predialysis, for the most part, and her blog is excellent, it's a great resource she talks about very valid things related to kidney failure. She talks about; I read a little bit about, something about sleep apnea. She does traveling; she has her own book on kidney failure. I will put the link to her blog into blog posts, where she talked about my book, but you can also explore her blog, and I will put that link in my show notes, and come over and see that and checkout Gail Rae. I'm so excited to get to talk to other people who have blogs about this topic and I may even try to have her on the show.

Alright, so now we are going to talk about, we are 5 1/2 minutes into the show, and we are finally going to talk about the topic, and I wanted to talk about kidney support groups. This month is all about taking care of yourself, having a healthy start, creating a healthy day, and to me a healthy part of having kidney failure or being a caregiver to someone with kidney failure, is taking care of yourself, emotionally and physically. So physically you take care of yourself with the doctor and one way that you can take care of yourself emotionally is with kidney support groups. I wanted to talk little bit about a kidney support group that I know that's a very successful and if you're interested in connecting with them you can even do it online. It's the Bay Area Association of Kidney Patients and their affiliated with the National Association a Kidney Patients. They are a resource and we connected early with a woman named Linda Umbach, and she is one of their director people, and she's also volunteered for the National Board for AAKP for kidney patients. I know she has a wonderful story and they are doing things like regular meetings, they announced the regular meetings that they have locally, and they are in California obviously. They also have an online forum where you go in and asked some questions and they have informative webinars. It is an excellent resource, the website; they just recently had something about the maker of the artificial kidney. You can go there you can sign up for their webinars, you can read on the forums, and it is BAAKP.org and again I will have that listed on the blog post or the show notes for you.

For a few minutes I wanted to talk about why you benefit as a caregiver or as a patient, from being involved in a kidney support group. First of all, hearing from others going through the same events as you, can be significant. Sometimes the care providers, like

doctors or the nurses, will say, well it is usually this way, or it is sometimes this way, or most the time it happened this way, and you can start to think that you're the only one who feels that way. I have as another thing listed that others out there are going to the same struggles, that is significant, to feel like someone else is going through the same thing you're going through, you suddenly realize everybody has a problem with this type of connector and giving their bag to hook up, or we can get a ride together because they go to dialysis at the same time in the same place as me and now you have somebody to talk to, when you wouldn't have talked to that person before, or predialysis, you have someone now that maybe you can spend some time with and you guys can talk together and share as caregivers, share some responsibly, so maybe you can even come over and have tea and give the person a little bit of relief. That is an opportunity to see others are going to same struggles.

Your care providers are doing the best, obviously, and they have the experience but they don't experience it on the same level as the patient, and so it is good to hear from other patients. You do need to be careful and realize that it's not necessarily medical advice, but is good to get that feedback. Just ask, hey is this how you see it, or is this how you went through it. They can answer some questions and they can help you have a feeling of empowerment, so if you're feeling frustrated and all this isn't working, I can't seem to get this to work, then they can help you with the steps and give you that feeling like yes you can do this, you can get through this. That is a very significant thing for you as a care providers, or as a patient to feel like, okay, now I know what to say to my doctor, I want to try different medicine, or I want to work on exercising and now I have someone to exercise with, that's great!

Fourth, kidney disease is an emotional and a physical journey, just like I talked about earlier, and support groups help with that emotional journey. It is critical to take care of that emotional side. If you're feeling like you are frustrated and angry and you have got all this stress, you need to find a way to relieve some of that and support groups can do that for you by helping you get with other people to let off some of that steam. It's helpful to the care providers as well, when I say care providers, I'm talking about doctors and dietitians and nurses, we hear your side of it, in a way that maybe we don't always listen to when we are quickly and that minute in the office with you. So if we come to give a presentation at a caregiver group, and then we get to hear your feedback and your questions, we realize these are the things that we need to make sure were taking care of. But it is a good way for patients to get to interact with caregivers, kind of on a less formal basis as well. It is a time to listen and learn things you didn't even realize you need to learn. So you may not have realized that before you start dialysis, they are going to want to do a Fistula. If you don't know what a Fistula is, you don't have to worry about it, but if you didn't realize that, and then all of a sudden you're still in denial, you are still approaching dialysis and it's kinda comes upon you, it's better to know about a little bit ahead of time. You can get some of that from reading books and from understanding, but it is always better if maybe somebody can help you, and they might even help you accepted a little better and deal with what's coming next and help you understand that it's not the same way that you think it is going to be or there's other ways that it could be, it doesn't necessarily have to be this specific way that you think.

You may have a feeling it is going to be tied to a certain event and they may help you to realize that, no, you don't have to do hemodialysis in the clinic for four hours every day, or every other day. You can do it at home, or you can do peritoneal , or here's a place where I eat all the time and they're really helpful with food when I make requests, and that sort of thing, that you didn't even realize you needed to learn, that you didn't even realized that were problems or could be problems, are good things to get to be aware of.

Starting a caregivers group, if you wanted to start a support group because you don't have one that you can go to, or you feel like your doctor's office, maybe you go to a nephrologist, and you talk to the nurses, and you talk to a lot patients in the area, and there are no support groups and you want to start one, there are some resources, and I will put some links in the show notes for the resources. You don't have to be a doctor, you just have to be careful with making medical recommendations, but most the time you are going to have people in, and you are going to maybe read a book together as a group, and talk about things. Sometimes it could even be an opportunity just to not talk about kidney disease tonight, because it's our night off from doing that.

I just wanted to take a minute and go over and remind you that those are out there and it is a great opportunity for you to reach out in the world, deal with some of those emotions that you're having, have a better emotional experience and feel some things.

Finally, I wanted to talk about the fact that this week I just published a book, number ten, and is called, Sexuality and Chronic Kidney Disease, and it talks about the sexual issues that people have, whether it be, how they feel about how their body looks, or how their medications make them feel, or the loss of libido, all those things are covered in the book and of course it's on Amazon, so if you're interested just go to my author link which will be in the links on the website but it is renaldietHQ.com/go/author and go there and it will be listed on my page, and it's both Kindle and CreateSpace, which is the paperback version, so that's available.

So once again, today I talked about kidney support groups and I talked to you a little bit about some connections I've made, I kind of gave you a little review of what I'm getting ready to complete and what I've been working on. Again, if you want a discounted price on that CCD diet book, before it is released, and I'll send you a link to it, send me an email by February 5, 2014 to podcast@renaldietHQ.com and I look forward to talking to you again next week, thank you very much.