



A Young Man's Dialysis Journey

The Past

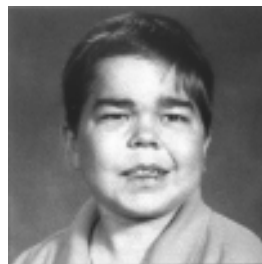
Brian Hess is a 17-year old hemodialysis patient from Oklahoma. His artwork is featured in the 1999 American Kidney Fund calendar for the month of July. Brian's dialysis journey began in 1988 when he was six years nine months old. At this time Brian's kidneys were starting to deteriorate.

During this time Brian attended school at Country Estates Elementary School in Midwest City, OK. Brian did well in school and participated as much as he was able. He and his family were open with the school and his friends about his condition. As a result Brian enjoyed the support of his school and friends as he learned to deal with his life with kidney disease.

By 1991 a decision had to be made on the treatment that Brian would have for his kidney disease. At this time Brian's father donated his kidney for transplant. The teachers and students at Brian's school held a walkathon to raise money for Brian's family to help with expenses. Brian expressed, "I was happy so many people at school were willing to

help me."

At first everything was working out well for Brian with his transplant. After a year there started to be



Brian Hess

took his own kidneys. His first transplant failed after two years. When the kidney failed, Brian was placed on hemodialysis. His school, Monroney Junior High, worked with the family so that Brian could get his treatments and still keep up academically. They were supportive and understanding when Brian did not feel well after a treatment.

In the years since then, Brian has received 2 more transplants, one from his mother and one cadaveric. Unfortunately, these both failed as a result of Brian's disease. It was determined, after the third failure, that transplantation would not be an option again for Brian. Brian returned to hemodialysis and remains on this treatment.

complications. Brian's transplanted kidney started to develop the same disease that

The Present

Brian dialyzes three times a week at his facility. For the past year he has been able to drive himself to treatments. This has allowed Brian to be more independent and relieve his mother of this task. His school, Midwest City High School, works with Brian so he can keep up with his schoolwork and get his treatments. Brian serves as the manager for the high school football team this year. When asked, "How has kidney disease made things different for you than your peers?" Brian responded, "It made me grow up faster, I had to learn responsibility quicker and I can't play sports." "What was the hardest thing to adjust to?" Brian responded "being shorter than all my friends." "How are you the same as your peers?" "I'm a regular high school kid who likes the same things and is as smart and mature as my peers." Brian emphasized that, "being a kidney patient is only part of who I am."

Brian's artwork is featured in the AKF 1999 calendar for the *JOURNEY* - Continued on p. 4

"Glad You Asked That . . ."

QUESTION: *Peritoneal Dialysis, Pro or Con?*

ANSWER: Lifeline or noose, which one of these would I use to describe peritoneal dialysis for me? Hello, my name is Carolyn Wilson-Davis, and I have been on Peritoneal Dialysis (PD) for 4 years now. For those of you who don't know my journey, I was on Hemodialysis (HD) for approximately 6 months and have undergone two unsuccessful kidney transplants.

I decided, in between all of this, to try PD. Well, the first year or two did not go very well. Even though I accepted that I needed to do this procedure in order to survive, in my mind I was still in denial. I took my doctor's prescription for my PD, and I made my own prescription! As a result of this, I went through several painful episodes of peritonitis. Eventually, I had to have my exit site moved, which was no fun at all!

After all of this, I then decided it might be a good idea to do this the right way. I personally love the flexibility of PD, but hate the feeling of confinement once I am connected. I love being free in the evenings to enjoy doing things with my son, and spending family quality time without having to take 3 or 4 hours every other evening to spend sitting in a clinic. But, there are pitfalls!!

My husband works late some evenings and is sometimes pretty late getting home at night. I am always pretty leery once I am

hooked up that something may happen, that I would not be able to protect my son, who would be sound asleep. If I get cold, I can't get to the thermostat. If I decide that I am a little thirsty, I am unable to make it to the kitchen! The greatest inconvenience is needing to get off the machine and discovering that you used your last cap and the others are in the next room!

There is what I call, "the temper tantrum syndrome," when I decide, "I don't feel like going through the trouble of setting the machine up. I'm already in the bed and sleepy. I'll do it tomorrow."

Thank the Lord for my husband who comes in every night from work, goes right to the supplies and brings me a box! When I say, "I'm not hooking up tonight," he replies, "And why not?!" So, after debating the issue for 10-15 minutes, I am no longer asleep. So, I get up and setup the machine. He wins again!

The next morning, when I open my eyes, get up to get dressed for work, get my son ready for school, and we get ready for another day's venture, I realize it is not my husband who won again. It was I!

The realization is that with every worrisome hook-up I am blessed with another day in the land of the living. This can also be said for HD or transplantation. Each day is a battle to make it for the next day, and the next day, etc.

The pro's and con's for each modality differ for every individual in ev-

ery situation, but we are all fighting the same battle and can help support each other by turning the hindrance into a stepping stone.

-Carolyn Wilson-Davis

Peritoneal Dialysis (PD) is a treatment choice that should be discussed with you when choosing the type of dialysis treatment you will have. You must be able to perform all the requirements of this treatment. Having an available helper may facilitate performance of PD. You will be trained by the facility staff on how to perform the dialysis. Supplies will be shipped to your home and will be coordinated with your dialysis facility. Access care will be taught and is an important responsibility of the patient. PD adequacy is greatly reliant on the patient following their prescription and doing the required exchanges. The Network has been low in reporting PD adequacy numbers and this is a concern. It is extremely important that you as
ASK - Continued on p. 3

If you have any questions for "Glad You Asked That," forward them to ESRD Network 13, 6600 N. Meridian, Suite 155, Oklahoma City, OK 73116-1421, or phone 1-800-472-8664. Selected questions will appear in future issues of *Kidney Concerns*.

Kidney Transplant

Every now and then I have to stop and remind myself that my transplanted kidney is just a treatment, not a cure. Taking my medications has become so routine that I go for weeks at a time without even thinking of my kidney.

The fact that I am an ESRD patient does not even cross my mind. I hope I don't sound ungrateful for my sister's donation or for my second chance at an unrestricted life. My health is better than it was years before my kidneys failed. I'm free from the rigors of dialysis schedules and complications. I travel freely. I have no kidney related diet restrictions. For these things, my gratitude is boundless.

Unfortunately, not all ESRD patients are as fortunate as I am. Due most often to advanced age or poor overall health, some are not candidates for a kidney transplant. The rest of us are eligible for transplant evaluation and able to take advantage of a second chance at a less restrictive lifestyle. Why, then, do some choose to stay on dialysis rather than opt for a transplant?

Although I cannot speak for

them, let's examine a few reasons why some otherwise good candidates may be reluctant to receive a transplant.

Let's start with fear of surgery. It is true. Implanting an organ is major surgery. However, as major surgeries go, and I've had a few, it's more like a minor-major surgery, if I may coin a new medical term. Most patients are often up and walking in just a few days and out of the hospital in a few more. Many can expect to return to daily living activities in a short period of time. However, there are risks to any surgery, and patients must decide if the reward of a less restrictive lifestyle is worth those risks.

The idea of being wed to a lifetime of daily medication is often cited as a reason for not having a transplant. Some of the medications have adverse side effects and some are potentially serious. In fact, I have developed diabetes. I feel that these reactions are a small price to pay for my freedom.

Now, if I have made a convincing case for transplant, the next question is, "where do I get one?" Many kidneys come from cadavers. Historically, most organ recipients have received their transplant from a cadaver. There are other options.

Many people have siblings, or other close relatives with whom they are tissue-compatible. These people are potentially good living, related donors. Still others may have a spouse or friend that may qualify. Organ transplant from living but unrelated donors is another viable option.

We cannot escape a discussion of the costs. Who pays for my work-up? Who pays the donor costs? Who pays for the transplant and my care after? There are many potential funding sources, such as Medicare, Medicaid, private health insurance and personal monies.

My intent in writing this article is to cover the subject of kidney transplantation with a broad brush and an eye toward convincing those eligible patients who may be somewhat reluctant to consider a transplant. In subsequent articles we will discuss these subjects in more detail as well as other areas of interest to those considering transplantation as a treatment option.

For further information, contact your local transplant center.

-David Broach

ASK - Continued from p. 2

a patient bring in the **required samples as instructed by your dialysis staff.** We will not get a clear picture of PD adequacy until this is accomplished. Your health can become compromised if the dialysis facility cannot accurately determine your PD adequacy and make the adjustments to your prescription that may be needed.

Brian Moore

author of
Striving for Empowerment
presents
five commandments
for the empowered patient

- Thou shalt be responsible for thy own healthcare**
- Thou shall not be a victim**
- Thou shalt be informed**
- Thou shalt not settle for less than complete answers**
- Thou shalt be a person first, and a patient third**

JOURNEY - Continued from p. 1

month of July, which is Brian's birth month. "How did you get selected for the calendar?" "I got a 1998 calendar then sent in for an entrance form for the 1999 calendar. I picked the month I was born in and drew a picture of what represented that month."

Brian sent in his artwork to AKF. He had not thought much about it when in September he was notified that he was selected to be displayed in the calendar. "What do you think about having your artwork and photo going out around the country?" "It's pretty neat. I haven't won anything this big before." Our congratulations go out to Brian for his accomplishment.

The Future

When questioned about what the future holds, Brian holds the same dreams as his peers. "I want to be independent, get out on my own, live my life. I want to go to college and work towards a medical degree. I would like to be a pediatric nephrologist. My own experience would help me in working with young people with kidney disease."

Brian has a plan to accomplish this, and if his past is any indication of his ability to achieve what he sets his mind to, we will have a new nephrologist in the next millennium.

Brian did not get to this point alone and wants to thank and acknowledge the help he received from his nephrologist, staff at his dialysis and transplant facilities, his friends and most importantly his family. They have all helped Brian learn how to cope and adjust to his kidney disease and its influence in his life. Brian would like to especially recognize his mother for her dedication to him and for "always being there for me and taking care of me."

When asked if he had any advice for other young people faced with kidney disease, dialysis and/or transplant, Brian stated, "never give up and always believe in yourself. You can be a regular kid and live a full life as a kidney patient. You can be whatever you want." This wisdom could benefit any kidney patient. Good luck with the future, Brian. The nephrology world is awaiting your arrival.

Louisiana

The Network would like to recognize two centurions from Louisiana:

Camelia Hughes, hemo patient from Hammond, born 10/15/1898.

Edna Toorean, hemo patient New Orleans, born 9/21/1898.

Arkansas

- Lawmakers support increase for kidney program budget. The Arkansas Kidney Disease Commission will receive \$40,000 over the biennium to help supplement the Medicare, Medicaid, and private insurance costs of treating end-stage renal disease patients.
- Renal Service Group of West Memphis will be sponsoring a kidney fair May 15, 1999. Contact Wilhelmina Cager at (870) 733-9534 for more information.

Oklahoma

- Robert Washington, a hemodialysis patient, from TRC-Shawnee is a Vocational Rehabilitation Counselor for the Iowa Tribe. He was recently appointed to an advisory board that reports to the Governor of Oklahoma on vocation rehabilitation issues.
- The Oklahoma Nutritional Network (ONN) and the Oklahoma Health Care Authority (OHCA) are partnering to provide diabetes-related services, medications and products for Oklahomans. A total of \$3,000,000 has been budgeted for these services. If these types of services are needed by you contact your facility social worker who can contact OHCA.



KIDNEY KONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SUMMER/JULY. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Concerns

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