



KIDNEY CONCERNS

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WHEN THE CHIPS ARE DOWN . . . CHIP ISN'T

Most people would say Chip Austin has it made. He's a 27 year old senior at the University of Arkansas where he is studying to be an Electrical Engineer. Chip has interests in electronics, computers, astronomy and writing. And, like his older sister, Karen, he lives with kidney failure.

One might think it a cruel twist of fate for a young man with such diverse dreams and aspirations to be stricken with kidney disease. Chip doesn't see it that way.

Actually, he began his accomplishments early on. As a young boy, Chip designed and built a "plairpocycle" out of an old golf cart, bicycle, riding lawn mower, lumber and odd pieces of hardware. The name, like the craft itself, came directly out of Chip's imagination. He and his friends then rode this one-of-a-kind, boy-sized racer at the speed of gravity down the hilly streets near his home.

A few years later, in ninth grade, Chip turned his gaze upward to the stars. After spending some time with his school counselor looking through a telescope, Chip set to work on a telescope of his own. Over the course of a few months, he built three telescopes, eventually combining them into a single

45 inch, 180X power reflective telescope. Chip shared his love of astronomy and his telescope with members of a local stargazing club.

Electrical Engineers use computers. Computers caught Chip's eye about the time he became a teenager. His first was a Commodore VIC-20 which he purchased with coin-savings when he was in the seventh grade. On this he taught himself the BASIC programming language. He eventually upgraded to a Commodore 64.

By his senior year of high school, Chip's interest in computer programming had graduated from simple text to graphics. He wrote a graphics design program, Sprite Designer, a program which he felt would make an excellent science project. His expertise and hard worked won him recognition in the local, regional and state science fair competitions.

These days Chip taps the keys of a PC. Not satisfied with the hype of the local computer salespeople, Chip researched the components for his latest computing device. Armed with knowledge of processors, hard drives and cooling fans, Chip assembled the

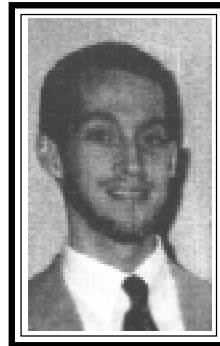
necessary parts and built his system himself.

Chip has even tried his hand at biomechanics. During the long hours of dialysis, the legs can become sore and knotted. To help him stretch his leg muscles, Chip devised, crafted and put to use a device he calls a "foot press" so that he would not have to inconvenience others with this chore.

Chip's latest accomplishment is really the culmination of years of fascination and study of Bible and world prophecy. He has written a book entitled Alpha and Omega, a Study of the Beginning and End of Time wherein he discusses the relevance and concurrency of prophecy to historical fact.

Chip Austin, dreamer, accomplished engineer, computer programmer and author. What next? Chip intends to bring his talents to bear in the world of robotics and artificial intelligence.

Chip credits his success in life and his high spirits in the face of grave medical difficulties to his faith in God and his family's support. This young man from Arkansas has a lot to give and fully intends to do just that.



Chip Austin

"Glad You Asked That . . ."

QUESTION: *Why are some people, who are on the transplant waiting list, transplanted sooner than others?*

ANSWER: The question of why some people on the transplant waiting list are transplanted sooner than others often arises. To understand the answer, one must understand the policies for organ allocation. Organ allocation is the system that determines who will receive an organ for transplant. The job of determining how human organs are allocated among the many people waiting for a transplant falls to the United Network for Organ Sharing (UNOS). UNOS has been under contract with the federal government since 1987 to be the organization that sets the organ allocation policies. This is done with the authority provided by the National Organ Transplant Act (P.L. 98-507) and is called the National Organ Procurement and Transplantation Network (OPTN). The policies set by the OPTN are subject to review and approval by the federal government. Until these policies are reviewed, compliance by the hospitals and Organ Procurement Organizations (OPOs) is voluntary.

Many factors influence who first receives an organ for transplant. Medical urgency is one of these factors. Thus, people who are the sickest are given a degree of priority. These are the people that would die without a transplant. Also included

in this category are children as they are more likely to suffer from growth and developmental problems due to their disease processes.

Another important factor to consider is the length of time a person has been waiting for a transplant. Those who have been on the waiting list the longest are among the first to be

people are given extra consideration because it is difficult to find suitable kidneys for them.

A further example of these conditions is the person's blood type. A person who is blood type "O" can only receive organs from a donor of the same blood group. Organs from a blood type "O" donor can, however, be transplanted into persons of any blood type. This means that organs from these donors would most likely be given to persons of other blood types, making fewer organs available for type "O" patients. To prevent this from happening, the current system requires that most kidneys from type "O" donors be given only to type "O" recipients.

As one can see, many things are taken into consideration when determining who receives an organ for transplant. The fact that organ transplantation is an ever growing and changing field requires that policies and procedures related to all aspects of the field be continually updated.

by Susan K. Haraway, RN, CPTC

Factors Which Influence Who First Receives an Organ Transplant:

- Medical Urgency
- Length of Time a Patient has Waited for a Transplant
- Medical or Biological Disadvantages

of - ferred an organ for transplant.

Something else that affects the amount of time a person waits is if they have medical or biological disadvantages. These are conditions that make it more difficult for them to receive an organ for transplant. An example of this is if a person waiting for a kidney has high levels of antibodies against foreign tissue antigens know as Human Leukocyte Antigens (HLA). These antibodies can develop as a result of blood transfusions, pregnancy or previous transplants. In the current system, these

If you have any questions for "Glad You Asked That," forward them to *Network 13*, 625 N.W. 13th Street, Oklahoma City, OK 73103-2239, or phone 1-800-472-8664. Selected questions will appear in future issues of *Kidney Concerns*.

WORKSHOP EMPHASIZES PATIENT EMPOWERMENT

As a renal patient and a nurse I am always in search of workshops that partner renal patients and those who care for them in order to achieve optional health outcomes through creative teaching programs. Just such a program was presented in the December 6th conference, "Positive Outcomes Through Partnership: Creative Education for Renal Patients" sponsored by the American Kidney Fund and Amgen in Dallas.

This conference was an all-day workshop that focused on educating nurses, dieticians and social workers. It emphasized innovative teaching methods that encourage participation by the patient and interested

family members in all aspects of the patient's care. The program also introduced outstanding educational programs presently in use at certain dialysis and transplant facilities.

Speakers for the conference represented several areas in the teaching of patients including nurses, dieticians, social workers, the patient and patient family members. Each speaker presented their role in moving the patient toward a healthier life. All renal patients must know information regarding nutrition, decision making, exercise and cultural diversity. Speakers not only provided information, but did so in such a way that included the patient and family

members in all aspects of care. These were also presented in a way that not only taught the patient, but was also interesting enough that patients would be motivated to actively participate in their care.

Doug and Lori Strickland are a patient/family team that stressed the importance of the patient taking an active role in their care and the necessity of family support. This family is an excellent example of the independence a patient can achieve when he is knowledgeable about his disease and has optional support from family members.

by Penney Pilkington

NATIONAL KIDNEY FOUNDATION OFFERS NEW EDUCATIONAL PROGRAM "PEOPLE LIKE US, LIVE!"



For anyone who's been diagnosed with chronic kidney disease, the National Kidney Foundation's new "People Like Us, Live!" program will answer everything you ever wanted to know about life with kidney disease.

"People Like Us, Live!" is a six-part workshop series which will address issues such as the different types of treatment available, transplantation, nutrition, coping, rehabilitation, sexuality and finances. The workshops, to be held April 19-20 from 10:00a.m. - 2:00p.m. and 1:00p.m. - 4:00p.m., will be offered by the National Kidney Foundation and are open to family members as well.

"People Like Us, Live!" is designed to provide participants with unbiased information they can trust and the emotional support they need in order to make treatment and lifestyle choices that work for them.

The first workshop will be held in Little Rock on April 19-20. For further information, call the National Kidney Foundation of Arkansas at (501) 664-4343.

The American Kidney Fund is pleased to announce its 1997 Regional Conference Series: **IMPROVING RENAL TREATMENT OUTCOMES IN A DIVERSE COMMUNITY**

The future of renal treatment will certainly include outcomes measurement. This conference will describe the projects that are currently underway to define and measure quality care for ESRD patients. It will showcase programs which have led to improved outcomes in various areas of renal treatment and will explore methods of implementing quality improvements programs with an increasingly diverse patient population.

CONFERENCE SCHEDULE

Chicago -- May 30th
Atlanta -- September 19th

New York -- June 27th
Baltimore/Washington -- October 17th



For more information, call Rae Kelley at 1-800-638-8299 x122.

PAC Speakers Bureau, Up and Running

The Patient Advisory Committee's (PAC's) Speakers Bureau is up and running! Two committee members have had speaking engagements with groups in the renal community over the past few months.

Richard Reeder, an Oklahoma PAC member and former PAC Chairperson, spoke to a small group of incenter, hemodialysis patients at a facility in Midwest City, OK. Penney Pilkington, a

long-time PAC member and transplant recipient, spoke to about twenty-five transplant recipient (TRIOS) members in Little Rock, AR. And, on another occasion, Ms. Pilkington spoke to twenty members of the Adult Medical Surgery group, also in Little Rock.

If you would like one of the PAC Speaker Bureau participants to speak to your group, please contact the Network 13 office at 1-800-472-8664.

Patient Alert!

One peritoneal dialysis (PD) patient's husband recently wrote to Kidney Concerns about a serious situation involving his wife. His wife had to take a trip out-of-state. While she was traveling she developed a problem with her access. She located a hospital, but it was not equipped to handle a PD emergency. Eventually, she cut her trip short and came home where she received treatment from her own doctor.

Today, she is doing just fine. But she learned a valuable lesson. If you are going to travel, check with your home facility. They can advise you before you leave and help you locate facilities along your route that can assist you in both routine and emergency situations.

Submitted by Randy Longstreath



If you've ever looked for a job, you know the importance of a good resumé. Here is some useful information on how to write your resumé.

Heading - Include your:

- Full Name
- Complete address (include permanent address and present address if you're a college student)
- Home telephone number (work number, too, if appropriate to contact you there)

Education/Training

- Names and locations of schools or programs
- Degrees, certificates or licenses awarded
- Major
- Grade-point average, if 3.0 or above
- Course work related to the job you want
- Honors, awards, scholarships, elective offices

Employment History - Be sure you cover full-time, part-time, summer and volunteer work; military service; internships; self-employment. Include:

- Names and addresses of employers
- Dates of employment
- Duties
- Major accomplishments

VOCATIONAL REHABILITATION

Activities/Special Skills - You may want to mention:

- Interests and activities which demonstrate job-related skills (leadership, organization, etc.)
- Personal accomplishments (i.e. "financed 70% of college education")
- Special abilities, such as knowledge of a computer language or a foreign language

Don't include personal data, such as age and health status, unless you're sure that information will work to your advantage.

References - Indicate that references are available, but do not list them on your resumé.

Job Objective - If you include a job objective, avoid being vague, but don't be so specific that you eliminate yourself from other closely related positions. Example:

GOOD: An entry level position as a writer in a public relations department or advertising firm.

POOR: A challenging position that uses my education and creativity.

For more information on how to write a resumé, consult your local Vocational Rehabilitation Counselor or visit your local library.



KIDNEY CONCERNS 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:

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