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## DIALYSIS AROUND THE WORLD

# Family Focus

The Renal Community's Newspaper

VOLUME 10 NUMBER 2

SPRING 2001

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## Dialysis Outcomes and Practice Patterns Study

By Donna Mapes, DNSc, MS

**T**he Dialysis Outcomes and Practice Patterns Study (DOPPS) is an international study taking place in seven countries: France, Germany, Italy, Japan, Spain, the United Kingdom and the United States. These seven countries represent more than 75 percent of all hemodialysis patients in the world. This study will identify the relationship between hemodialysis practice patterns and patient outcomes of mortality, hospitalization, vascular access and patient-reported quality of life. This is the first international study of its kind. The goal of the study is to increase the understanding of the differences in patient characteristics and the differences in practice patterns among facilities and to compare those differences to patient outcomes.

In the United States (US-DOPPS), data collection began in 1995. In Europe (Euro-DOPPS), data collection began in 1998, and in Japan (Japan-DOPPS), it began in early 1999. Over 306 facilities have participated, which represents over 10,000 patients. Patients are continually replaced if they leave the facility for any reason and the patients selected as replacements are new to the facility. The facilities selected in each country are representative of the facilities throughout that country. Also, the patients participating in the study are randomly chosen from each facility. Because of the design of the study, we can say that the findings can be applied to all hemodialysis patients and dialysis facilities in the seven countries.

Many preliminary analyses have yielded very interesting information. We now know for sure that

hemodialysis patients in the United States have a considerably higher prevalence of diabetes, cardiovascular disease and other co-morbid conditions compared to Europe and Japan. In other words, many patients in the U.S. are sicker than their counterparts in Europe and Japan. This is also true of the general population of the U.S., so it is not surprising to find this in hemodialysis patients. Another preliminary finding is that some patients "skip" their dialysis treatments on occasion in the U.S. This virtually does not happen in the other countries. And, "skipping" treatments appears to be associated with a higher risk of mortality.

Vascular access practices are also significantly different in the U.S., where many patients use a graft for vascular access instead of a native A-V fistula. The use of catheters is also quite high in the U.S. The analysis show that a correctly placed A-V fistula lasts much longer on average than a graft or catheter. And, in Europe and Japan, the majority of patients use an A-V fistula. In fact, in Italy the nephrologist, not the surgeons, have been trained to do fistulas, and they place the vascular access. You might assume that these differences exist because U.S. patients with diabetes and/or cardiovascular disease may not have "good" blood vessels to support an A-V fistula. However, in the preliminary study, the differences between the U.S. and Europe/Japan remain even when less sick patients are compared.

The DOPPS study has been gaining an international reputation and is widely recognized as an authoritative source of information on hemodialysis patients and their outcomes over

time. University of Renal Research and Education (URREA) is the international coordinator, and Philip Held, PhD, is the principal investigator. The Study Coordinating Committee comprises Dr. Held, Dr. Mapes, and co-investigators from the University of Michigan and Amgen, Inc.

*Donna Mapes, DNSc, MS is director, nephrology professional services and DOPPS project director of Amgen.*

## Hemodialysis In Kosovo

By Wendy Brown, MD

**T**his past summer, along with Dr. Mark Adams, chief of the abdominal transplant service at the Medical College of Wisconsin in Milwaukee, I had the opportunity to



**Dr. Wendy Brown (third from left) and medical personnel in a dialysis unit in Gjilan.**

travel to the Yugoslavian province of Kosovo as a consultant to the World Health Organization. Our task was to evaluate the care of patients on dialysis and look for opportunities to decrease the cost. This experience made me realize how fortunate we are to be living in a country where we

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## FROM THE EDITOR

**D**ialysis Around the World was a very fun

issue to put together for you. Its focus is two-fold. First, we want to encourage you to continue enjoying your life after kidney



Karren King

failure. We want you and all of those around you to realize that you can continue doing most of the things you enjoyed prior to beginning dialysis. This definitely includes traveling for leisure or business but also other very important aspects of your life, such as exercise, work, volunteering, school, socializing, hobbies...the list goes on and on. But, those are topics for another issue of *Family Focus*! Travel comes in all shapes and sizes. There are cruise ships that accommodate those on dialysis. There are also camps, which are not only for children and adolescents with

kidney failure, but also for adults and entire families. You might want to dialyze throughout the United States over long periods of time, visit family, or simply head to the mountains or lakes in your own area for a few days. Whatever your interest, as the familiar Nike ad tells us..."Just do it!"

This issue also has an international flavor. We thought it would be fascinating to learn about dialysis experiences in other countries. As we explore care that is provided for those with kidney failure around the world, we sometimes find that we should feel very blessed to have the health care that is available to us in the United States. However, we also realize that we can definitely learn from others and possibly enhance the care that is provided here.

We hope that this issue sparks your interest in traveling, wherever your destination. A change of scenery occasionally can do all of us a "world of good." Go for it and enjoy!

Karren King, MSW, ACSW, LCSW  
Editor  
For the Editorial Board

## We Dedicate This Issue...

It is with sadness that we dedicate this issue of *Family Focus* to Dr. Peter Lundin, who passed away in March. Being both a dialysis patient and a nephrologist, Dr. Lundin brought a unique perspective to kidney disease. He began dialysis in 1966 and remained on hemodialysis until his death, except for five years with a kidney transplant. Dr. Lundin was the director of the dialysis unit at Kings County Hospital in Brooklyn, New York. He was also a professor at the State University of New York Health Science Center. A founder of the American Association of Kidney Patients, Dr. Lundin was a compassionate and collaborative partner to the National Kidney Foundation. His contributions were many, and he was a true leader for the national renal community. He will be greatly missed.

### The More

#### YOU KNOW

### Travel Tips: A Guide for Kidney Patients and Their Families

If you are planning a trip, you can get lots of helpful information by consulting the National Kidney Foundation's booklet, "Travel Tips: A Guide for Kidney Patients and Their Families." This guide provides many tips on:

- \* making arrangements for dialysis treatments while you are away
- \* arranging for backup medical care at your travel destination
- \* paying for treatment when traveling
- \* following your special diet
- \* taking your medications away from home.

The guide also covers patients' specific travel concerns. For example, patients who are on a transplant waiting list learn what to do to avoid losing their place when they are out-of-town. Special sections provide information for:

- center hemodialysis patients
- home hemodialysis patients
- peritoneal dialysis patients
- transplant recipients
- patients with diabetes
- patients who are HIV-positive.

To obtain a copy of the guide, contact your local National Kidney Foundation affiliate, or call the national toll-free number (800) 622-9010. 



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*Opinions expressed in this newspaper do not necessarily represent the position of the National Kidney Foundation*

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# Government Regulation of Dialysis Clinics: Past, Present and Future

By Dolph Chianchiano, MPA, JD

European dialysis clinics appear to have more patient care staff per patient than those in the United States, according to preliminary unpublished data from the Dialysis Outcomes and Practice Patterns Study (DOPPS). Nurses in these units appear to be better educated. However, final analysis must be undertaken to see if these differences remain.

In the United States, the federal government has regulations that govern the organization, staffing and operation of dialysis clinics. These rules are known as "conditions of coverage" and they have been in effect since 1976. We want you to be informed about these conditions so that you can appreciate the regulations that affect your care. The government has proposed publishing a draft revision of these regulations in the coming year. You might want to be prepared to comment on how these revisions might affect you.

The current conditions of coverage specify the qualification of personnel who should staff your dialysis unit. They also specify that an adequate number of personnel be present whenever you are undergoing dialysis so that the patient/staff ratio is "appropriate to the level of dialysis care being given and the needs of the patients." These mandated staff positions are:

a) Physician director who is board-

eligible or board certified in internal medicine or pediatrics and who has 12 months' experience or training in the care of dialysis patients.

b) Dietitian who has received a baccalaureate or advanced degree with major studies in food and nutrition or dietetics and who has at least one year of experience in clinical nutrition.

c) Nurse with at least 18 months of clinical nursing experience (including experience in the care of dialysis patients) who is licensed as an R.N. and who is responsible for the nursing service in the dialysis clinic.

d) Licensed Social Worker who has completed a course of study with specialization in clinical practice and holds a masters degree from an accredited graduate school of social work.

There were few dialysis technicians working in dialysis units when the conditions of coverage were introduced in 1976, which might explain why the regulations do not mention dialysis technicians.

In addition to staffing requirements, the conditions of coverage include a statement of patients' rights and responsibilities, with the goal that all patients will be treated with consideration, respect and full recognition of their individuality and personal needs. Every facility must involve you (or your parent or legal guardian) in the development of a written plan for your care. Additional requirements relate to the physical

environment in which ESRD services are furnished, dialyzer reuse, and arrangements for the care of patients who experience medical emergencies.

Although federal regulations do not specify a patient/staff ratio, the state of Texas has such a requirement. The Texas Administrative Code requires at least one licensed nurse be available on-site for every 12 patients and the equivalent of one full-time dietitian for up to 100 patients, with the maximum patient load per full-time equivalent dietitian being 150 patients.

The trend in federal regulation is towards reducing requirements rather than increasing them. The rules governing hospitals and home health agencies have already been streamlined. Furthermore, the Clinton/Gore Administration issued a document called "Reinventing Health Care Regulations," which states that revised regulations for ESRD facilities must increase flexibility in providing dialysis services. It describes a pilot project to evaluate the impact of eliminating Medicare personnel requirements for ESRD facilities entirely.

If you want to stay on top of this and related issues, you are invited to join the National Kidney Foundation's grassroots advocacy network by calling (800) 889-9559.

Dolph Chianchiano is NKF's director of scientific and public policy. 



## MAIL BOX

I just received a copy of Family Focus and I would just like to say thank you for sending it to me all the way to England. I found your publication informative and enjoyable, and look forward to the next one. Keep up the good work and thanks once again.

Andy Short, London/UK

Dear Sirs:

My husband was introduced to the world of dialysis five months ago, during which time we have learned a lot and continue to learn a lot more about the intricacies of hemodialysis.

I particularly enjoy reading the Poetry Corner, which inspired me to write my version of hemodialysis after we had gotten over the initial shock and were learning to adjust to the treatments. I am enclosing a copy to share with you.

Thank you for all of the good work you do on behalf of the dialysis patients, and for the encouragement you offer to all of us as we struggle to cope with this lifetime commitment

Sincerely,

Rosemary Joslyn  
Wichita, KS  
(Husband - Keith Joslyn)

## Traveling Tips For the Dialysis Patient

By Napoleon (Toby) Austin

**M**ost new dialysis patients wonder if they can still travel. Although some may be afraid at first, vacationing can be fun if you plan ahead. I work for Renal Care Group of the Midwest as a regional patient services coordinator, arranging dialysis for traveling patients. I was on hemodialysis for six years before I had my transplant eight years ago. I want to share some tips to make your vacation as problem-free as possible.

People on all types of dialysis can take weekend trips, camp, travel overseas or even take dialysis cruises. Your social worker or travel coordinator can explain your options.

### Traveling with Hemodialysis

After you pick your destination, decide how you will get there and how you'll get to and from dialysis. If you fly, do so on non-dialysis days and don't make reservations until a facility agrees to accept you. If you travel by car, know how long it will take to get there. If you plan to sightsee or visit friends or family, you may need treatments along the way. Although some home hemodialysis patients have trailers with their machine and supplies so they can dialyze on their schedule, most do center hemodialysis when they travel.

Arranging center hemodialysis takes planning. Whenever possible, give your written request to the unit clerk, social worker, or nurse who coordinates travel at least 30 to 60 days in advance. In emergencies most facilities will do their best to accommodate shorter notice. Your request should include :

1. Your name and phone number
2. Destination address including city, state and phone number
3. Area of the city you would prefer for your dialysis treatments
4. Preferred treatment dates/times

Flexibility is essential. A facility may schedule you for your requested dates, but if they have new patients starting who need those dates, their permanent patients' needs usually have priority, and your reservation may be changed or even cancelled. You may dialyze at other than your

usual time. If you normally dialyze Monday-Wednesday-Friday and the unit near your destination can only schedule you on Tuesday-Thursday-Saturday, your home unit may adjust your treatments temporarily to get you ready for this change.

Sometimes there isn't an available facility near where you wish to visit, or all are full or unable to accept traveling patients or to meet special medical needs, such as having an isolation area if you have hepatitis. Your travel coordinator will work with you to arrange dialysis as close as possible to your destination.

Check with your nephrologist about any special medical instructions for your travels. The visiting unit's nephrologist will review your records and write dialysis orders based on your doctor's prescription. Although the nephrologist at the visiting facility may meet with you, your doctor at your home unit is also available to you while you travel.

Long before your trip, your travel coordinator will send the following medical records to the dialysis facility you plan to visit:

1. Visiting Information Sheet (this is usually provided by the unit you are visiting)
2. Standing orders
3. Medication list
4. Lab results drawn within 30 days of your first away treatment
5. Hepatitis antigen drawn within 30 days of your requested treatment date(s). [If you had the hepatitis vaccine and have antibodies, these results may be accepted if drawn within the past 12 months.]
6. Most recent history and physical examination
7. Psychosocial assessment
8. Patient care plan
9. Last three dialysis treatment flowsheets
10. Last hospital discharge summary
11. Long-term care plan
12. Medical Evidence Report (HCFA 2728) form
13. A copy of your health insurance card(s) and/or a pre-authorization form from your PPO/HMO if applicable.

### For more information on travel, see the following:

- Travel Tips: A Guide for Kidney Patients, National Kidney Foundation (800) 622-9010 and in the Internet A-Z Guide [www.kidney.org/general/atoz/](http://www.kidney.org/general/atoz/)
- Just the Facts: Traveling on Dialysis (Keys to a Long Life fact sheet), Life Options Rehabilitation Program (800) 468-7777 and at [www.lifeoptions.org/teachtools/travelfs.pdf](http://www.lifeoptions.org/teachtools/travelfs.pdf)
- Searchable listing of dialysis facilities with maps at [www.dialysisfinder.com](http://www.dialysisfinder.com).
- Searchable lists of dialysis facilities in the U.S.: [www.esrdnetworks.org/Units.htm](http://www.esrdnetworks.org/Units.htm)
- Searchable list of dialysis facilities in U.S. and overseas in The List from *Dialysis and Transplantation* magazine, which is available in most dialysis and transplant facilities and at [www.eneph.com](http://www.eneph.com)
- International travel information [www.globaldialysis.com](http://www.globaldialysis.com).

You should carry a copy of all of these records when you travel.

During your last treatment at your home unit, ask your travel coordinator for contact information on each facility you'll visit, your dialysis appointment times, and whether the facility you're visiting wants you to bring your most recent medical records. Confirm your appointment with the visiting facility when you arrive.

### Travel with Peritoneal Dialysis

You don't need a reservation at a dialysis unit if you do peritoneal dialysis, although you should have a backup facility at your destination in case you have a question or problem. Some want to receive medical information in advance. Others suggest you carry information similar to that needed for hemodialysis treatments. If you're going for a weekend, you can carry supplies in a suitcase or in your car. Some people on CCPD take their machine and

*continued on page 5*

# On the Road to Fitness

By Susan Carey, MS, ACSM

**T**ravel is a fun diversion from everyday life. We all enjoy a break from our routine to visit family and friends, or explore new places. However, there are some routines, like dialysis and exercise, that we must continue even while traveling. It is important that we continue to exercise regularly to maintain fitness and a sense of well-being.

While preparing for your trip, keep your exercise routine in mind. Call ahead to find out your options. The friends or family members you visit may belong to a gym that will allow you to use their facility either free of charge (as a guest), or for a small day-use fee. Find out what type of equipment they have, and if they offer classes that might interest you. You may also want to call the dialysis unit you plan to attend while traveling. It may have an exercise program or equipment, such as exercise bikes, that can be used during your dialysis session. If so, be sure to get written permission from your nephrologist to exercise at that dialysis unit.

Be sure to pack exercise gear appropriate for the climate you will be visiting. If you will be in a cooler climate, consider exercise clothing that can layer easily, as well as gloves, and even headgear. Alternatively, if you are visiting a tropical or warm climate, be sure to pack clothing that allows the body to cool appropriately and don't forget the sport sunscreen. If you will be visiting a different climate, allow your body to adjust to the change in temperature by gradually exposing yourself to the climate during initial bouts of exercise. Then, increase your exercise sessions gradually in both duration and intensity. Likewise, in a cold climate, be aware of how your body is responding to the temperature. Early warning signs of cold injury are a tingling and numbness in the fingers and toes, or a burning sensation of the nose and ears (McArdle, Katch, and Katch).

If you are visiting a friend who would like to take you skiing or snow shoeing, you must consider the effects of altitude on your ability to exercise. At altitude, we often realize that the air is "thinner," meaning that the density of the air is decreased,

leaving us with a decreased partial pressure of oxygen. For this reason, it is more difficult to "catch our breath" at altitude.

It is important to allow yourself to gradually adjust to altitude before pursuing vigorous activity. As a guideline, you will need about two weeks to adapt to an altitude of 7500 feet and an additional week for each 2000 feet up to an altitude of 15,000 feet. If you are anemic or prone to anemia, the oxygen carrying capacity of your blood is decreased. This will cause the effects of high altitude to be pronounced and possibly dangerous. If this is the case, you must check with your doctor before traveling to areas of high altitude to which you are not accustomed (McArdle, Katch, and Katch).

Once you adjust to your new environment, allow your exercise sessions to be unique opportunities to spend time with friends or relatives. Rather than making a date for lunch, ask your friend to join you for a walk, hike or bike ride. It creates a healthy opportunity to chat while keeping up your exercise routine. If you are exploring a new city, try walking or riding a bicycle to view the sites. There's no better way to pick up on the details of a new area than by walking its streets and interacting with the local people.

Traveling to visit distant family or friends, or simply exploring new areas are valued luxuries. To better enjoy your visit, maintain your sense of well-being by continuing with exercise and proper health care. It's not difficult to do and can be an enjoyable part of your visit. Bon voyage!

## References

McArdle, Katch, & Katch. Essentials of exercise physiology. 1994 Lea & Febiger, Philadelphia. 

## Traveling Tips...

*continued from page 4*

supplies with them on vacation, even on planes. Other CCPD patients do CAPD when they travel. For longer trips, peritoneal dialysis suppliers can ship supplies to your destination and hotels will hold them for you.

### Health Insurance Coverage

Check with your insurer, social worker, or travel coordinator if you don't know what your insurance covers when you travel. Medicare pays for dialysis in the United States and its territories. Commercial insurance and some Medicare supplements may pay for dialysis outside the U.S. If Medicare is your primary insurer, many facilities require you to pay the 20 percent balance left after Medicare. Some will bill you or your insurance company directly. If you pay the 20 percent, your insurance company will usually reimburse you if you document your medical expenses. If you must bill your insurance company yourself, ask for a receipt and Explanation of Medicare Benefits.

Medicaid (or Medi-Cal in California) pays for dialysis at contracted facilities. Most are in your home state but some may be in towns near your state's borders. Ask your social worker or Medicaid caseworker if the dialysis facility at your destination takes your Medicaid. If not, ask what your financial responsibility will be.

Finally, when you travel, watch your diet and fluid gains, arrive on time at the visiting facility, and obey all rules, including those about eating or having visitors during your treatment. During my six years of dialysis I enjoyed several trips that went smoothly, thanks to some preparation. With a little planning, patience and flexibility, you, too, can enjoy traveling with dialysis. 

## Upcoming Issues:

Complimentary and  
Alternative Treatment

Kidney Disease and  
the Life Cycle



We invite you to submit contributions to the Editorial Board.

Please send submissions to:  
National Kidney Foundation,  
30 East 33rd Street  
New York, NY 10016.

# Medical Issues for Safe Travel

By A. Peter Lundin, MD

**N**eeding a large machine to stay alive, with treatments three times a week, seems like a sure prescription for not traveling. That is what almost all who find



Peter Lundin

themselves on hemodialysis believe. Not true. While traveling as a hemodialysis patient can be intimidating, I have climbed the Great Wall in China and rafted down the Salmon River in Idaho, "the River of No Return." More simply, hemodialysis for travelers is available on every continent except Antarctica, and there is probably some entrepreneur ready to set up dialysis there once enough patients are ready to do it.

If you are afflicted with the wanderlust there are a number of medical issues you should attend to before planning a trip. The last thing you need is to spend your vacation days in a strange hospital being cared for by doctors unfamiliar with you.

1. Make sure your blood access is working well. Make sure that your last measured dialysis treatment had a good Kt/V or URR. It might be worthwhile to have one measured just before you go on your trip. Check your venous pressure (ask your nurse to show you how), making sure that it is not high or rising from treatment to treatment. If your unit measures the blood flow in your access, have it done before you go to make sure the flow is not dropping or low. Any of these things could indicate that your access is about to fail.

2. Be confident about your diet. I am not an advocate of continuing the "renal failure" diet for dialysis patients. It is a diet of "don'ts" rather than a diet of possibilities. In many dialysis units patients are told what they can't do or what they have to do, rather than how to make life on dialysis more tolerable. With good dialysis you should be able to eat more normally, but with attention to not eating so much salt and potassium that your blood levels become life-threatening. You should learn to eat in relation to your next dialysis treatment, being aware that you might have to delay dialysis for a

day because of access problems or trouble getting to the unit.

End points are important. Do not eat so much salt that the resulting water weight gain causes problems during dialysis or shortness of breath before dialysis. A pre-dialysis potassium up to 6.5 meq/L will not cause harm. If that is your pre-dialysis level of potassium after one day between treatments then you should be more careful during the two days off. Do not be afraid of eating good amounts of protein, but make sure to make up for that with extra phosphate binding medicine.

3. Learn what kind of food you will encounter on your travels. If these foods are different than what you are used to, you will need to learn about their potassium and salt content. There may be other problems with local foods. For example, if traveling in the tropics, avoid star fruit, or carambola, which can be poisonous to dialysis patients. Find out, ahead of time if possible, from the dialysis unit where you are going, what foods you need to be careful with and which are good for dialysis patients. Being prepared will allow you to enjoy eating while traveling.

4. Be aware of the proper way to stick your access. Know what kind of access you have and which are the arterial and venous sides. A person who has never seen your access will be sticking you. Is it a graft or fistula? Upper arm fistulae may be confused with grafts. The puncture technique is different for grafts and fistulae. If the wrong technique is used, infiltration of blood into the arm can occur. Worse, the access may be destroyed. If the needles are put in backwards you may not get a very good dialysis. Best of all, learn how to put in your own needles. The anticipation of the stick is much worse than the actual needle pain, and you will never miss your access when sticking.

5. Remember to take all of your medications. In other parts of the world some of your medicines may have other names or may not be available. Trying to get a prescription from a doctor who doesn't know you or at odd times of the night or weekends could leave you without

important medications. Start lining up your medications several days ahead, making sure you have enough to cover the trip and for a few days after you get home. Put your medications in your carry-on bags so in the event that your luggage gets lost or rerouted you won't have to worry about replacing your lost medicine.

6. Take a medical summary with you. It would be nice to have the summary in the language of where you are going, but that is most often not possible. Most doctors around the world read English and probably speak it a bit also. The medical summary should include any allergies, important diagnoses such as diabetes or heart disease, and a complete list of your medications. Such a summary is particularly important if you have to go to a hospital for any reason.

7. Be sure to contact the dialysis center(s) where you will be receiving treatments well ahead of time. If you planned a trip and delay too long in arranging for dialysis, you could find yourself without a place for treatment. I know patients who, having failed to make arrangements for dialysis, went anyway, expecting to go to an emergency room if they got sick. Several of them have died in the attempt. After getting a confirmation from a dialysis center, contact the center again a week or so before the date of your trip to reconfirm.

With a little advance preparation and a few precautions you should be able to enjoy your trip. Go for it!

A. Peter Lundin, MD was a nephrologist at SUNY/Downstate Medical Center in Brooklyn, NY. 



# PATIENT AND FAMILY CORNER

## Traveling With Dialysis

By Brent L. Smith

**A**re travel and dialysis treatments possible? Throughout the country and likely around the world, dialysis patients travel on a regular basis and have a great time while doing it. You can, too!

There are limitations to destinations for dialysis travelers but patients do motor down the highways, ride buses and trains, and even fly the largest of planes routinely, hoping to enjoy new exciting places. However, it does take planning to travel with confidence and ease.

Are you considering taking a business trip that you initially thought was impossible? Go ahead and enjoy the opportunity to make it happen. Being a dialysis patient does not limit your capabilities to travel or vacation. But you must believe you have the ability to do it! I would like to share what I think helps patients like myself gain the ability to travel.

First, plan your trip. Ask your social worker for the Dialysis Providers Guide or a similar list of facilities that will accept traveling dialysis patients and make the first contact yourself. Being a dialysis patient for about 20 years, I have experienced great and not-so-great situations when leaving the comfort of my own dialysis unit.

One time I attended a rest and relaxation retreat in Amelia Island, Florida. It was fun, but I made mistakes by not arranging hemodialysis treatments myself at a unit closer to where I was staying. I wound up traveling a far distance for treatment and it made my daily plans impossible. Although my treatments were extremely important, I did miss the golf outing because of how far I had to go to reach the unit!

Second, plan in advance. At least 30 days before you travel, make a phone call to the unit where you would like to receive your treatment to talk about your plans to schedule transient dialysis. Talk to the person in charge of scheduling treatments, and ask for a written commitment for your dialysis schedule. Discuss special needs you may have when at their unit. When a unit agrees to dialyze you, advise your social worker about the dialysis center location, the dates of treatment, and the name of

the person who has been contacted. This helps if your social worker needs to contact the unit to clarify insurance questions.

Third, prepare and bring documentation about your medical condition, insurance, prescriptions, dialysis treatment and IV medication, as well as copies of your last three treatment run sheets. The unit will dialyze you according to "their" protocol if you do not have standing orders about "your treatment" prescription with you. Do not depend upon others to forward information about your dialysis treatment.

Nervous or afraid about traveling? Start on a small scale. Plan a trip within driving distance of your home and try one treatment away from your own unit. One way to experience the "difference" you may feel when traveling is to ask your administrator to arrange a "field trip" for you. If your dialysis company has other units nearby, ask to dialyze elsewhere for one treatment to learn how to schedule things, while pretending you are traveling across the continent. Some of you may not have the option to practice a field trip at another unit that is affiliated with your own. Don't give up! Try

another town and schedule a treatment there. It is the practice of scheduling dialysis that you want to experience.

Dialysis and travel should not take the fun out of travel plans. If you liked to travel prior to kidney failure, then continue to enjoy it by making compromises. Dialysis treatment removes fluid and poisons from the body and blood. However, it does not remove the wanderlust in many a traveler's heart. Remember my three successful travel tips:

1) locate the unit where you want to dialyze, 2) start making plans at least 30 days in advance, and 3) hand carry a copy of your dialysis prescription to document your specific treatment.

I hope to meet you the next time I travel. Life is meaningful when dialysis and travel can come together to make business opportunities and vacations really happen. Tell a friend!

Brent Smith began hemodialysis in 1973. He received a kidney transplant in 1974 and again in 1977. He returned to hemodialysis in 1990 and is currently awaiting a kidney transplant. 

### Vacation and Dialysis Travel Tips

By Dale Ester

S S T R A N S K I E N T S N D I A Y L Y  
S I N I S A L R N L O N W E S M C W E E  
N T S O O T R O A V O E F P L N A A N X  
D U S Y I T I W I I L R L H E H A L V C  
E F M U L T N L T V I F T R H X F L Z H  
E Z W B A A A P N E T Q R O L S E E Q A  
R P W C E P I C N O J U T L D B A T N N  
U B A J U R L D I H C N Z O A P N C O G  
S V Q R C P S L O D E N A G S E C I Y E  
A I S S Z H E J I M E J G I I P S C T S  
E E E G O T O Z P Y E M G S V R U A I K  
L R E Q R E M I M D Z H N T E E P P L R  
P C M I T Q U T U L C A M V Y O B D I K  
D D E A P Q I Z P H R K N M L B L L C Y  
H S R E E H N R O T C O D I I N K G A B  
Q J G O W K O P J B C E C D M D T G F D  
B S E V N U Z N N B Q I S H A R K J F W  
D K N P O S D I E A U X H R F F Y E K J  
I Z C P N D X A U S G Y M S U K G P O M  
Q T Y B E C F U N B O Y F J X N M G W B

### Words to Search

CAPD	MEDICATIONS
CASH	NEPHROLOGIST
CCPD	NUMBERS
CONVERSION	NURSE
CURRENCY	PHONE
DOCTOR	PLEASURE
EMERGENCY	PRESCRIPTIONS
EQUIPMENT	PURSE
EXCHANGE	RATE
FACILITY	TOILETRIES
FAMILY	TRANSIENT
FRIENDS	VACATION
FUN	WALLET
HEMODIALYSIS	WORK

Answers to puzzle on page 15

## Hemodialysis In Kosovo

*continued from page 1*

may complain about medical care and its costs, but know it is available to us.

The health care system in Kosovo presents some unusual challenges. For 10 years, prior to the June 1999 return of power to Albanian



**Dialysis patient Peje is cranking back blood during a power interference.**

Kosovars following the NATO bombings, Albanian Kosovar health care workers were not allowed to work in hospitals or attend medical or other professional schools. During that period, they set up an underground medical system, treating Albanian patients and carrying out medical education secretly in basements and private homes. These patients were sent to Serbian hospitals only when they were too ill to be cared for in the underground system.

We met a vascular surgeon and his thoracic surgeon father who had an operating room in their home and performed open chest surgery without blood transfusions! Unfortunately, the Albanian health care workers did not have access to new medical books or journals and, therefore, most medical practice and knowledge is nine to ten years out of date. When the Serbs left, much of the hospital equipment was disabled or destroyed so that the Albanians could not use it. Most medical books not written in the Serbian language, were destroyed. Albanian Kosovars returned to the hospitals, though many had never worked in a hospital or had not for the past 10 years. They had a lot of "catching up" to do.

There are only three kidney doctors, or nephrologists, in Kosovo,

all in the Pristine Hospital Center, to care for a population of two million people. When we visited in June, there were 264 patients on dialysis in five hospital dialysis units. That means that about 155 patients per million population were receiving dialysis in Kosovo compared to 644 million patients per population, on average, in other countries in the European Union.

The four units outside of Pristine were directed by doctors who were not trained as kidney doctors, but who had learned a lot about dialysis. During the war, many Albanian dialysis patients moved to other countries so they could have dialysis. The number of patients on dialysis has been increasing quickly because former patients are moving back to Kosovo while new patients are now starting dialysis.

The typical dialysis patient in Kosovo is very different from the typical patient here. There are very few patients who have diabetes. The average age is about 40 to 45 years, compared to over 60 in the United States. There are only six patients under the age of 20 there. Most children and older patients are not sent to a kidney doctor. When resources are scarce, the very young, the very old and those patients with serious chronic disease do not get treated. Only one patient performs peritoneal dialysis. Kosovo does not have a transplant program. Occasionally, children are transplanted in another country with money donated by a charity.

Dialysis in Kosovo is a humbling example of doing much with little. Overall, the quality of dialysis care is very good, considering the age and poor condition of water treatment and dialysis machines and the lack of many laboratory tests and medicines. Only 10 to 15 percent of patients die there each year, but it is important to remember that they tend to be much healthier to begin with compared to many patients in this country. We did not see any overweight dialysis patients!

Most dialysis machines are very old and have been used much longer than they should have; some more than 40,000 hours. Machines that do not work are taken apart to fix other machines. Machines in Prizren did not have air bubble

detectors – they were all broken. To prevent fatalities from air entering the system, one health care worker is assigned to each patient to detect bubbles in the tubing.

EPO is not available; low blood count is treated with transfusion. Hepatitis B vaccine is not available and many patients and staff have hepatitis. Medicine to prevent bone disease is available only occasionally. They are unable to measure PTH (parathyroid hormone), which is a hormone that when produced by the body in normal amounts helps to maintain healthy bones. This hormone tends to be present in large amounts in patients who are on dialysis. If these high levels are not treated, patients can develop serious complications.

The cause of kidney disease is frequently not known because kidney biopsies are not done. They do not have biopsy needles, the kidney doctors have not been trained to perform biopsies and they do not have the materials to look at the biopsies properly – they are far too expensive.

Lack of equipment is not limited to the dialysis unit. There are, of course, no CT machines or MRIs. One of the operating rooms had an overhead light, but it was not mounted. Sanitary facilities are poor: two of the dialysis unit staff bathrooms were "French latrines"—flat porcelain slabs with central holes and footrests. Most of the bathrooms had no sinks or only cold water with cloth towels and no soap.

The most valuable resource in Kosovo medicine is the fierce thirst for knowledge demonstrated by their young doctors and nurses. While we were in Kosovo, together with Zina Munoz, an emergency room nurse and computer network engineer, we provided the kidney unit with a computer and printer, access to the Internet and medical books on CD-ROM. It is important that these young people receive modern medical information and clinical training in countries such as the United States and those in Western Europe so they may share their new knowledge with their colleagues back home. 

# PD The CParent Connection

## CAMP CHIMER A Special Place for Kids

By Hayley Biegel and Morgan Ghosey



Hayley (right) and Morgan (left) are counting the days till summer camp starts again.

**W**ant to meet kids from all over the United States, do fun activities and get away from your parents for a week? You can do all of these things and more at Camp Chimer. Sponsored by the Children's Mercy Hospital in Kansas City, the Dream Factory and the National Kidney Foundation of Kansas and Western Missouri, Camp Chimer is a camp for kids who are on hemodialysis or peritoneal dialysis or who have a kidney transplant. You can begin attending when you are nine years old and you can go every year after that until you turn 17. When you are age 18, you have to take a year off, but you can come back as a junior counselor the following year if you're lucky.

There are a lot of fun and exciting things to do at Camp Chimer for kids of all ages. You can boat or fish at the lake, swim, do arts and crafts, camp and a lot more. Every year there is a big, fancy dinner where the doctors and nurses are the waiters and waitresses, and then there is a dance. Everyone comes and has a great time getting their groove on! Before the dance, hairstylists come to do the girls' hair (and some of the guys, too), and the nurses do our make-up and nails. After the daytime events are done, most nights end with a campfire where we sing songs and hang out with new and old friends.

People have donated a lot of things to make our camp great. For the last couple of years we have gone to

Worlds of Fun, a large amusement park, and spent an entire day there. We have attended a Royals baseball game and we have even rented a whole bowling alley. We know everyone had a blast there!

Camp Chimer is a place where the kids and counselors are honest, friendly and willing to help you with a smile. At the end of camp, when the week is over and you are completely exhausted, everyone still finds it dreadfully hard to go and many campers keep in touch with their new friends throughout the year. Camp Chimer is a fun getaway from home, but just like home, it is hard to leave!

Camp Chimer is something all kids with kidney problems should experience. The two of us met each other at camp five years ago and we look forward to seeing each other and meeting new friends there every year. We always have a perfect time with lots of great memories that we will never forget!

Hayley Biegel is 13 years old and lives in Salisbury, Mo. She previously was on PD, but received a kidney transplant four and a half years ago (She had to leave camp to receive her kidney). Morgan Ghosey is also 13 years old and lives in Olathe, Ks. She was on PD for nine and a half years and received a kidney from her father in December 2000. 

## NKF Kidney Camp Directory Available

Each year, parents, children and health care professionals look forward to receiving the National Kidney Foundation's "Kidney Camp Directory." It provides a listing of day and sleep-away camps throughout the United States that accommodate kids with kidney disease and their families, as well as some for transplant recipients of all organs. While most of the camps are for children up to age 17, some accept kidney patients of any age. The majority are in session during the summer, but some take place in the

spring and fall. Some accept out-of-state campers. The majority of camps listed in the directory are sponsored by NKF affiliates.

The "Kidney Camp Directory" provides tips to assist you in making the right camp decision. Camps are listed by state and include information on the location, sponsor, accessibility, cost, scholarships, camp dates, registration deadlines, activities, age guidelines and transportation assistance. The directory also has a listing of NKF affiliates, and

an overview of the Patient & Family, National Donor Family, and transAction Councils for kidney patients, donor families, transplant recipients and their families.

To request a copy of the NKF's "Kidney Camp Directory," call (800) 622-9010, e-mail [pfc@kidney.org](mailto:pfc@kidney.org), or visit the Patient & Family Council's Web page at [www.kidney.org/patients/camp.cfm](http://www.kidney.org/patients/camp.cfm) 

# T R A N S P L A N T

## R A N S P L A N T

### So You Are Waiting For A Transplant...

by Linda Harte Hatfield, RN, BSN, CNN, CCTC

**C**ongratulations! You have met with the kidney transplant team and they have established that you would be an acceptable candidate for transplantation. Now what? Depending on your blood type, the wait for a kidney could last from six months to three years. So, don't sit by the phone with your life on hold. You should continue to participate in normal activities.

One of the most important things you can do is to dialyze according to your schedule. If you skip a dialysis treatment and are called for a kidney, there may not be time for dialysis before the transplant. Take your medications as prescribed, and watch your diet and fluid intake. You need to be healthy when you are called for a transplant. You will not be able to go to surgery if you have any new medical problems or signs of infection. Maintain contact with your transplant coordinator and let him or her know if you are hospitalized, have the flu, a cold or any infections. See your physician as soon as you have symptoms of a cold or flu, as he or she may be able to prescribe medications to help.

When activated on the transplant list you must be available 24 hours a day. It is very disappointing to the transplant team when they are unable to reach you, and of course, disappointing for the person who has missed a call. Give your transplant coordinator a list of phone numbers where you might be reached. Most patients use a pager or a cell phone and some transplant centers have temporary access to free pagers for potential recipients. If you are interested, contact your transplant center to see if one is available. Remember, a cell phone or pager is only

useful when turned on. Turn it on every time you are away from home.

As your transplant coordinator told you, you may receive "false alarms" before you get the real call for your kidney. Whenever there is a donor kidney, of the same blood type, a potential recipient list is drawn up. The patients who are number one and number two on the list are called first because they have the most number of points. Points are accumulated based on how long you have been on the list, how many antigens you share with the donor and how many antibodies you have. Even if you are number four or five on the list you will probably receive a call to make sure you are not sick. You could be told that you are first, second or third runner up for the kidney if the top two cannot have the transplant. This can be one of the most confusing parts of the transplant to those waiting, so feel free to ask your coordinator about this process.

If you want to travel or attend special events, please carry on with your plans. Give your transplant center the phone numbers to your hotel, relatives and cell phone, and ask your pager company if it can temporarily upgrade you to a long distance pager.

Before you are activated on the list, your transplant center will require that you have certain vaccinations, such as those against Hepatitis A and B and a certain kind of pneumonia. If you are traveling outside of the United States, be sure to check with your physician to see if there are vaccinations that you need for your trip. You must protect yourself from any unusual illnesses that could be acquired in a foreign country. You should also notify your transplant center once you receive the vaccinations.

Usually, unless you are very far away, or staying in an area with a limited number of airline flights, you should be able to promptly return to the transplant center if you are called for a possible transplant. When the transplant coordinator

contacts you, he or she will estimate how much time you have to get to the transplant center. Remember, you will be called even if you are the back-up person. They must be sure there is someone available to receive the kidney. Most airlines will try to find you a flight if they understand that you must return home due to a medical emergency. You may want to carry a letter from your transplant center about your transplant status to show the airlines should this need arise.

As you know, when on vacation you may tend to "cheat" on your diet. However, keep in mind that if you are called for a transplant and are fluid overloaded or your potassium is high, there may not be time for dialysis.

There may also be times when you are traveling and you don't wish to return to the transplant center if a kidney becomes available. This in no way jeopardizes your chances of receiving a call the next time a kidney becomes available. If you want to enjoy a cruise with your spouse or attend a family reunion or wedding uninterrupted, by all means do it. If you know that you want to do this in advance, simply notify your transplant team.

Remember that when you are on the transplant list, you should stay healthy, follow your dialysis schedule, take your medications and watch your diet and fluid intake so that you are ready for that transplant. But, it is also important to stay active and do the things you want to do. You will still receive your transplant.

Linda Harte Hatfield, RN, BSN, CNN, CCTC is a renal transplant coordinator at Saint Luke's Hospital Kansas City, Missouri. 



# Plan Ahead For Travel

By Bobbie Knotek, RN, BSN

**T**ravel presents a unique set of challenges for people on dialysis. To help you meet these challenges head-on, use these plan-ahead travel checklists.

## Hemodialysis Travel Checklist

### Making Dialysis Treatment Reservations:

Talk to the person who makes dialysis travel arrangements at your clinic to determine your responsibility in scheduling dialysis treatment reservations.

- If traveling within the U.S., reserve dialysis treatments at least 6-8 weeks prior.

- For popular destinations like Hawaii, California, Arizona and Florida, reserve treatments at least 3 months prior.

- If you need holiday dialysis reservations, call for reservations at least 6 months to a year in advance.

When you call the host clinic, ask to speak to the person in charge of scheduling transient dialysis treatments. Give him or her the dates you will require dialysis treatments and any special needs (e.g., dialyzer, dialysis machine or isolation room).

- You may have to travel to a clinic some distance from your lodgings.

- **BE FLEXIBLE** - many clinics reserve certain days or shifts for transient dialysis. They may offer you a Tuesday-Thursday-Saturday schedule when you normally dialyze on Monday-Wednesday-Friday, or you may be asked to dialyze on their evening shift.

Write down the name and position of the person who scheduled your transient appointment. Ask for confirmation of the transient dialysis reservation in writing.

Ask the host clinic what medical records are needed and where they should be sent.

Most clinics require a dialysis prescription and schedule, hepatitis B status, most recent lab work, type of insurance, Medicare number and a recent medical summary. Some clinics ask for a recent EKG, chest x-ray or HIV/AIDS test. Clinics can only request HIV/AIDS tests on

transient patients if they perform this test on their own patients.

Ask if you need to see their nephrologist before starting dialysis treatments at the clinic. If so, find out how to make the doctor's appointment and what your cost will be.

Ask when you should call back to verify your transient dialysis reservation.

Ask the transient coordinator at your clinic to send the required medical records and insurance information to the host clinic.

Ask the transient coordinator at your clinic for an extra copy of your medical records and insurance information. Carry these records with you at all times.

### Paying For Transient Dialysis:

#### If Medicare is your primary payor

Ask the host clinic how you need to pay the 20% co-payment for your treatments. Some clinics bill the 20% co-payment to you, but many clinics require the 20% co-payment be paid in advance. Ask what forms of payment are acceptable.

#### If commercial insurance or an HMO is your primary payor:

Contact them for authorization to dialyze away from home.

Ask the host clinic if they will accept assignment of the 80 percent from your insurance. You may need a letter from your insurance stating they will pay for transient treatment.

Ask the host clinic what other charges you will be responsible for. If you are paying for transient treatments yourself, ask the host clinic what the total cost will be.

### Getting Ready to Go:

— Learn how to care for your fistula, graft or catheter.

Consider learning how to put in your own needles. This will help safeguard your fistula/graft.

Ask a staff person who is good with your needles to write personalized needle insertion tips for the host clinic staff.

Let your clinic know when you

will be leaving and returning, and when they can expect you back for dialysis.

Before you leave, call the host clinic to confirm your transient dialysis reservation date and time. Call 2 weeks before, 1 week before and the day before you leave.

Make sure your records have arrived. If not, ask your clinic to fax them right away.

Find out how to contact the host clinic's nephrologist when the clinic is closed.

- Cancellation of transient dialysis treatments is always possible due to factors beyond the clinic's control.

If your treatments get cancelled before you leave, ask for the names and phone numbers of other facilities in the area.

If your plans change and you do not need transient dialysis treatments, call the host clinic to cancel your treatments.

### Make a list of items you will need for the trip, including:

A list of your medicines.

An extra set of written prescriptions.

A copy of your medical records.

Phone numbers of your regular dialysis clinic and nephrologist.

If diabetic, take insulin, syringes, glucose monitor and monitoring strips, glucose tablets and hard candy.

If you do home hemodialysis and plan to take your machine and a portable water system on the road, take the 24-hour phone numbers for machine repair and medical assistance with you.

### During Your Trip:

Protect your fistula or graft:

- Do not carry luggage or packages with your access arm.

- If you fly, drive or take a train and have a leg graft, stand up and move around frequently to decrease swelling and pressure on your leg.

### When you arrive at your destination, call the host clinic:

Reconfirm dates and times of your treatments.



## Plan-Ahead For Travel

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- Give them your local phone number.
- Ask for directions to the clinic.

### Arrive early for your first transient dialysis treatment.

If you arrive and find your dialysis reservation has been cancelled, your options are: 1) try to find another clinic; 2) return home; or 3) go to the emergency room (ER) of a hospital that does acute dialysis. Most emergency rooms will evaluate you to see if an urgent need for dialysis exists. You may be asked to go home and come back to the ER at a later time, even if you have missed one or two treatments.

You will probably see dialysis procedures done differently than you are used to. If you have questions about anything you see being done, ask your caregiver. If you still have questions, ask to speak with the charge nurse.

Even on vacation, ALWAYS dialyze your prescribed number of treatments and hours.

## Peritoneal Dialysis Checklist

### Planning Your Trip:

- Ask your PD clinic to locate a back-up PD clinic near your destination. It helps to have access to a PD clinic if you get sick or have a dialysis-related problem.
  - Your PD clinic may send copies of your medical records to the back-up PD clinic. Most clinics ask for your dialysis prescription, Hepatitis B status, most recent lab work, type of insurance, Medicare number and a recent medical summary.
- Ask your PD nurse for an extra copy of your records. Carry these records with you at all times.
- Take the back-up PD clinic's name, address and phone number and the names and after-hour numbers of the PD nurse and nephrologist.
- If you use a cyclor, ask your PD nurse if you should cross-train on CAPD (in case of machine problems). If you are traveling to an area without electricity, you will need to learn CAPD.
- If you travel a lot, ask your PD

nurse to teach you to do tubing changes and how to add antibiotics to the dialysis bags in case of peritonitis.

Ask your PD nurse who you should call first for dialysis-related problems while traveling - your home clinic or the back-up PD clinic.

If you go to the emergency room or are hospitalized during your trip, do not let anyone who is not a PD nurse do anything with your PD catheter.

### Shipping Supplies to Your Destination:

- Notify your customer representative if you want your supplies shipped to your travel destination:
  - Supplies can be shipped to a residence or a hotel; ask if the manager will be your contact person and accept your supplies when they arrive.
  - For travel within the U.S., notify your representative at least 30 days in advance; for travel outside the U.S., at least 60-90 days in advance.
- If you plan to travel to several cities, mail an itinerary with the following for every city: date of arrival, delivery address, and name of the person accepting your supplies.
  - For delivery of dialysis supplies to a cruise ship, follow the time frame guidelines above.
- Ask to have your supplies delivered one week before you arrive.
- Tell the contact person what supplies are coming and when they will arrive. Ask to have them stored in a dry, inside area.
- Approximately four to seven days before you leave for your trip, call the contact person to make sure your supplies have arrived.
- Ask if the back-up PD clinic can furnish you with dialysis supplies if you run out, and how you would reimburse them for these supplies.

### Getting Ready to Go:

- Make a list of the dialysis supplies you need to bring with you and pack your own supplies - do not let a spouse or friend pack your supplies.
  - Check to see if there is a scale at your destination.
- If you are traveling by plane or train, pack these dialysis supplies in your carry-on luggage:
- Face masks

- Blood pressure cuff
- Dressing supplies for exit site care
- Outlet Port Clamps
- Mini-caps
- Heparin and syringes (if you have been taught to use heparin for fibrin)
- If diabetic, insulin, syringes, glucose monitor and monitoring strips, glucose tablets and hard candy
- An extra tubing set - ask your PD clinic for one and then return it after your trip if you do not use it.
- Travel hook or travel IV pole
- A waterless hand cleaner like Alcare or Purell (in case you cannot properly wash your hands before an exchange). Ask your PD nurse how and when to use these waterless hand cleaners.
- A list of your medicines
- An extra set of prescriptions
- A copy of your medical records
- Day/night phone numbers for your home PD clinic and nephrologist.

### If you do CAPD and you are flying or taking a train:

- Pack another carry-on bag equipped with everything needed to do 1-2 exchanges (in case you get stranded in the airport/train station)
- Plan to check several cases of dialysis solution (2 days' worth) in the baggage compartment.
- Do NOT ship your dialysis machine (cyclor, UV Flash, etc.) or check it as baggage. Carry your dialysis machine onto the plane with you. If you need extra carry-on space for your machine and supplies, arrange for this in advance.
- If you are traveling outside the U.S. with a cyclor or other electrically powered device, make sure you have the correct electrical adaptors.

### During Your Trip:

- Keep your medicines with you. Bring enough medicine for your trip and several days.
- If you are carrying a cyclor or UV Flash, tell everyone who handles your luggage that it should be

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## Plan Ahead For Travel

*continued from page 13*

handled carefully because it contains fragile medical equipment.

☐ If you have an airport layover or are stranded in an airport and need to do a CAPD exchange, ask an airline customer relations representative to locate a private place for you to do an exchange.

### CAUTION

- If you need to do an emergency CAPD exchange in an unusual place – consider the risks!

For example, it may be better to do an exchange in your car than in a gas station bathroom. (If you are traveling by car, ask your PD nurse for guidelines on doing an exchange in your car).

- Consider delaying the exchange until you get somewhere where the exchange can be done safely. You do not want to miss an exchange, but delaying an exchange may help you avoid peritonitis.

**Always remember – it's better to be safe than sorry!!!**

- Unless it is an emergency situation, DO NOT skip any of your prescribed CAPD exchanges or cyclor time.

A special thank you to the following Texas Peritoneal Dialysis nurses for their invaluable assistance in writing this article: C. Baldwin, RN (Gambro HC Houston), L. Fox, RN (Lubbock Dialysis – Redbud), S. Hinton, RN (Mockingbird Dialysis), J. Nishioka, RN (Methodist Hospital Outpt. Dialysis), C.S. Penberra, RN (NNA-North).

### Resources:

Lore, G. (2001). Balancing patient health and safety with vacation jaunts around the world is the goal of Dialysis at Sea Cruises. *For Patients Only*, 14 (1), 15-20.

Munschauer, C. E. (2001). Enjoying travel while protecting your vascular access and the PD catheter. *For Patients Only*, 14 (1), 21-23.

National Kidney Foundation. (1997). *Travel Tips: A Guide For Kidney Patients and Their Families* (Brochure). New York, NY.

Shaw, B. (1998). Advice for dialysis facility personnel and patients on how to arrange treatments prior to travel. *Dialysis and Transplantation*, L-3.

Smirnov, V. (1999). Transient dialysis. *Dialysis and Transplantation*, 28 (6), 333-334. 

## Travel Resources

Family Focus is pleased to provide you with the following travel resources. Keep in mind, however, that this does not constitute an NKF endorsement or recommendation of provided services. Also, we strongly recommend that you ask for personal contact references to verify satisfaction with services, particularly in the case of cruise lines, travel agents and lodging.

### How to locate a dialysis facility in the United States:

<http://nephron.com/usacgi.html> - This Web site has the Nephron Information Center which offers free information about dialysis units in the United States. The site includes maps and driving instructions.

[www.dialysisfinder.com](http://www.dialysisfinder.com) - Use this Web site to locate dialysis units in the United States by entering an address, zip code, city or state.

[www.medicare.gov/Dialysis/Home.asp](http://www.medicare.gov/Dialysis/Home.asp) - This is the Web site for the Dialysis Facility Compare, which is designed to help people choose a dialysis unit. When you enter the name of a specific dialysis facility, this site will give you information about the facility's ownership, location, size and clinical outcomes. Some of the information is based on older data, so you should always check with the facility for the most current information.

**The National Listing of Medicare Providers Furnishing Kidney Dialysis and Transplant Services** - This publication of the Health Care Financing Administration is a listing of all Medicare-approved dialysis and transplant facilities in the U.S. A copy can be obtained by writing or calling: Superintendent of Documents, U.S. Government Printing Office, PO Box 371954, Pittsburgh, PA 15250-7954, Phone (202) 512-1800, (Refer to stock # 017-060-00602-1)

"The List", published every year by *Dialysis and Transplantation* magazine, prints the names of dialysis facilities that offer dialysis treatments for people who travel. Your social worker may have a copy of "The List" or you can call (800) 442-5667 to purchase a copy. The cost is \$15.00.

### Specialized Travel Resources Within the United States:

[www.healthtalk.com/ken/toc/work/index.html](http://www.healthtalk.com/ken/toc/work/index.html) - This Web site offers advice and tips for dialysis travelers planning to travel inside the U.S. or overseas.

[www.kidneyfla.org/programs.html#kid](http://www.kidneyfla.org/programs.html#kid) - This Web site has information on the annual children's kidney camps sponsored by many local National Kidney Foundation (NKF) affiliates. To find out more about these camps for children with kidney failure, contact your local NKF office.

[www.uhcolorado.edu/vkc/about\\_vkc.htm](http://www.uhcolorado.edu/vkc/about_vkc.htm) - Vacation Kidney Center of the Rockies.

[www.dialysisatsea.com](http://www.dialysisatsea.com) - Dialysis at Sea Cruises.\*

<http://dtv.tierranet.com/> - Dialysis Travel & Vacations offers dialysis cruises organized jointly by STC Travel, a travel agency, and Scripps Dialysis Centers in San Diego.\*

[www.medicaltravel.org/dialysis/destinations.htm](http://www.medicaltravel.org/dialysis/destinations.htm) - Medical Travel, Inc. has cruises and land vacations for adults and children on all forms of dialysis. Dialysis while in port is offered by the Renal Association of Boca Raton, FL.\*

### How to locate a dialysis facility outside the United States:\*

<http://globaldialysis.com> - This Web site can help you locate a dialysis unit both in and outside the United States. The searchable site directory lists 10,200 facilities in 115 countries. The site includes links to lodgings, travel agents and tours that accommodate people on dialysis. There are also stories and travel tips from fellow dialysis "world travelers".

<http://renalworld.com> - This website has international listings of dialysis centers around the world.

\* Medicare pays 80% of the cost of transient dialysis treatments in the U.S. and U.S territories, including Puerto Rico, U.S. Virgin Islands and Guam. Medicare does not pay for dialysis on cruises, even if the cruise originates in the U.S. Medicare also does not pay for dialysis at clinics outside the U.S. or its territories. 



# The Dialysis Clinic at Chamonix, France

By Bob Skaggs, PhD

Since I was 31 years old, I have known that I have polycystic kidney disease. I was able to prolong the need for dialysis until 1995, when I was told that I would be on dialysis within the year. My wife and I began learning about dialysis, as we wanted to do it at home. During this time I was also placed on the transplant list at the University of New Mexico Transplant Clinic. We had planned to begin dialysis in April 1996, but on March 26, I received a phone call that I was a back-up for a transplant. The primary candidate refused the transplant, and I was the fortunate recipient.

From that day on, I have worked very hard to care for this very precious gift by watching my diet, exercising and taking my medication religiously. I have been a regular competitor and a medallist in the National Kidney Foundation's Transplant Games, as well as the World Transplant Games. I swim in the summer games and ski in the winter games. It was during the 1999 Winter World Transplant Games that I first met Dr. Phillippe Nicoud, and we have since become very good friends.

Dr. Nicoud fulfilled a childhood ambition by founding the Dialysis Clinic in Chamonix, France. As he was growing up in the nearby town of St. Gervais, he noted that people with kidney failure were severely limited in their enjoyment of outdoor activities in his beloved mountain region, surrounded by the French Alps and highlighted by Mont Blanc to the east.

Upon completing his medical degree at the Universite de Grenoble in 1986, Dr. Nicoud returned to his hometown to begin gathering funds and equipment to establish a dialysis clinic in Chamonix. The clinic serves two purposes. The first is to treat local people who need dialysis and treatment for all stages of kidney disease. The second is to have a clinic for people who want to enjoy the mountains and receive their treatment at maximum convenience to them. They can come to the area in both winter and summer and enjoy the beautiful scenery.

Depending upon the season, Dr. Nicoud sees 100 to 200 patients at all stages of kidney disease each year. Every

effort is made to assure that the local environment is as safe as possible for visitors, as well as the local population. The clinic also has some of the very latest equipment available, and some clinic staff do speak English.

I wanted to share this with those on dialysis in the United States who may have an interest in traveling to this part of the world. I hope that you will be inspired to go and enjoy the trip by knowing that you will be well cared for while there.

S. R. (Bob) Skaggs, who received a kidney transplant in 1996, holds a PhD in Materials Science from the University of New Mexico. He is retired from Los Alamos National Laboratory where he was a program manager.

The telephone number at the Mont Blanc Clinic is 011-33-4-50-53-22-00 and the e-mail is Phillippe.Nicoud@wanadoo.fr. 

## PUZZLE ANSWERS

### Answers to puzzle on page 7

Vacation and Dialysis Travel Tips Solution

PHRASE OR SOLUTION TIP

"transient dialysis allows me to travel and still have fun"

### Answers to puzzle on page 11

PLAN  
BINDERS  
PACK  
DIETARY GUIDELINES  
PREPARE  
SNACK FOODS  
MEDICATIONS  
PRESCRIPTIONS

MYSTERY PHRASE:  
HAVE FUN AND BE SAFE!

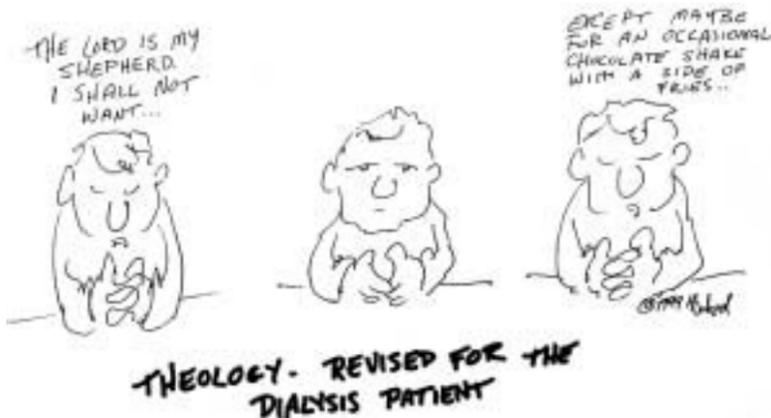
Are we  
missing you?

We'd like to make sure that NKF Family Focus is making its way to every dialysis unit and transplant center in the country. If we're missing anyone, or if you would like to receive a free copy at your home, please let us know by dropping us a note or by giving us a call at:

(800) 622-9010.

C A R T O O N

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Editor's Note: The artist, Lee Dolezal, was a cartoonist for his local paper. A kidney patient from Yorkville, Illinois, he passed away in November 2000.



# POETRY

## CORNER

### Security

By Jose A. Carmona

You guarded my sleep  
between three bared walls,  
one opened to heaven.

Laying softly within  
stiff rusted sofa chairs  
your eyes closed but permanently fixed  
on my restless dreams  
watching every move...

Cuddling in my hospital bed  
among the smells of ether  
and painful needle marks,  
I couldn't help but realize the  
comforting security  
a stranger had brought me by.

*Jose A. Carmona received his third kidney transplant in April 2000. He is a professor of Spanish and English and the chair of the Department of Modern Languages at Daytona Beach Community College in Florida.*

### "Anyone"

By Corliss Archer-Clark

Anyone can give up  
but it takes a soldier to be strong  
When trials and tribulations come our way  
God lets us know that we are not alone

No man wants to suffer  
But God asks that we just stand tall  
Though giving up seems easier  
On our life there is a call

So God sends to us our loved ones  
Friends and family to help us through  
But healing starts within the inner man  
Not giving up, is up to you

Anyone can give up  
But there is strength within every man  
To call forth those things that are to be  
And to know that God has a greater plan

*Ms. Corliss Archer-Clark is poet and evangelist. She has been on dialysis since September 1998.*

*Dedicated to all those suffering with life threatening illnesses...don't give up!*

### Life After Dialysis

By Rosemary Joslyn

"What do you mean, no salt on my meat?  
How do you think I'm going to eat?"

"And limit my fluids to a quart a day?  
If that's the case, I'd rather be dead."

The words of my husband as he ranted and railed  
When he first found out that his kidneys had failed.

The first treatments were rough, as we found our way  
To the dialysis center every other day.

Where he'd sit for three hours and watch the machine  
Take his blood all out and put it back clean.

And when he got home, "I'm exhausted," he said  
And spent the rest of the day in bed.

He adjusted to dizzy spells, chills and cramps  
Clogged arteries, needles, bandages and clamps.

"The nurses are nice," he said one day,  
"They cheer us up in their own special way."

And he began to observe during his three-hour wait  
There were a lot of people with the very same fate.

And I noted one day while driving him home  
He's beginning to realize he is not alone.

"He's looking better" our friends would say  
As he continued his treatments every other day.

Then I noticed myself how much better he feels  
I'd like to think it's my "salt free" meals!

So - we're learning to cope with this lifelong curse  
While some days are better and others are worse.

And we're finding out there is only one way  
To deal with dialysis - it's DAY TO DAY.

### Dialysis

By Tammy Keeler

D is for the despair I sometimes feel.  
I is for the isolation that comes my way.  
A is for the anger that has entered my heart.  
L is for the laughter that creeps into my soul.  
Y is for the yearning to be whole again.  
S is for the smiles from the staff and patients I see  
every time I go to the center.  
I is the illness that I will not lose myself to.  
S is for the strength that I get from friends and family.



National Kidney Foundation  
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