



A PROGRAM OF
RSN

Renal Support Network



The quarterly update helping educate and motivate people living with chronic kidney disease.

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Headline News

2nd Annual RSN National Patient Meeting Education Plus Friends Equals "Health, Happiness & Hope"

by Malia Langen, weKAN Patient Activist

The Renal Support Network (RSN) enjoyed spectacular autumn weather in Chicago when the famous "Windy City" welcomed close to 100 attendees for the 2nd Annual RSN National Patient Meeting, held at the Sheraton Hotel and Towers. For the second consecutive year, RSN's meeting was held in conjunction with the annual conference of the National Renal Administrators Association (NRAA).

The meeting, titled "Health, Happiness & Hope," took place over three days, September 29 through October 1, 2005. Patients and professionals alike became more informed on matters relating to kidney disease while getting to know one another and sharing



Patients discuss a variety of topics during the "Be Your Own Expert" luncheon.

their common experience.

Participants listened to speakers and panel discussions on a variety of topics. These ranged from medical awareness issues such as heart disease and new trends in transplantation, to personal growth topics such as keys to living successfully on dialysis and keeping a positive attitude. Many of

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RSN Report



"Music, Music, Music" Theme of 7th Annual Renal Teen Prom

For the seventh consecutive year, the Renal Support Network will be hosting a special prom for teenagers and young adults who have kidney disease. As in previous years, the Renal Teen Prom—to be held January 15, 2006, in the Los Angeles area—will be co-hosted by student and alumni volunteers from Notre Dame High School in

Sherman Oaks, California.

Set in the style of a senior prom, this free event draws more than 300 "kidney teens," their guests, and volunteers from throughout Southern California.

Last year's gala attracted kidney teens from Arizona and Texas, and teens from Canada will be coming to this year's event, evidence of the

prom's growing reputation.

With "Music, Music, Music" as the theme of the 2006 Renal Teen Prom, the teens will be treated to a night of dancing, karaoke, dinner (renal-friendly), limousine rides, and glamour "photo ops." Generous donations of gowns will allow every young woman to look elegant, and appearances by Hollywood celebrities will ensure a

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Uncertainty

by Lori Hartwell, weKAN President



The last couple of months have brought so much uncertainty, pain, and grief to people across the world.

Hurricanes, floods, and earthquakes have caused many to reconsider whether they can truly believe that things will ever get better.

Last December, I had to undergo double knee-replacement surgery. I really didn't have a choice, since it was becoming too difficult for me to walk without severe pain. Thirty-seven years as a kidney patient had taken its toll, along with years of ice-skating.

When I awoke from surgery, I was overcome with uncertainty, pain, and the profound question, "What in the world just happened to me!?" I could not do anything without help. I had no control.

The day after surgery, the hospital workers got me up to walk, but the

pain was unbearable. I felt like I would never be the same again. But if nothing else, my years of experience in dealing with one health crisis after another have taught me that "This too shall pass" and to take "One day at a time."

With the love and support of my family and friends and the skilled abilities of many healthcare professionals, I slowly improved. Walking around dependent upon a walker for six weeks gave me a deeper understanding of patience, for I often get impatient with myself when I think that life is moving faster than me.

Every other day for two months I had to go to physical therapy and undergo painful massages in order to remove or break up the scar tissue left over from the surgery. The hardest thing was making my legs stand straight (hyper-lock) so that I could stand for more than a minute at a time. I had the opportunity to talk with others who had gone through the same type of knee surgery. Hearing their words of encouragement, stories of hope, and ways to speed along my recovery helped me immensely.

The downtime surrounding my recovery gave me an opportunity to reflect on what I really want out of life. I spent time reading, making arts and crafts, and listening to music. Tapping into my creativity, which requires downtime to stir up, made my recovery smoother and faster.

My goal has always been to help provide patients with a platform from which they could help fellow patients by sharing with one another their experiences, strengths, and hope. This has been accomplished through RSN's Renal Teen Prom, the *RSN Directory*, the weKAN newsletter *Live & Give*, and the RSN National Patient Meeting "Health, Happiness & Hope." It's nice to see dreams come to fruition in the form of new programs designed to help fellow patients.

RSN's newest program is called PEPP (Patients Educating Patients & Professionals). PEPP comprises a series of educational programs to be led by patient-speakers. Its goal is to improve the outcomes of people with chronic kidney disease by increasing their knowledge of the disease, thereby encouraging involvement and self-management in their own care.

I am happy to report that when I reached three months post-double knee-replacement surgery, I was able to deliver a 45-minute presentation 3,000 miles from home. At six months post-surgery, my husband and I walked all over Boston on a personal guided tour led by former governor Michael Dukakis. At nine months post-surgery, I personally made 27 visits to congressional offices on Capitol Hill over the course of only three days.

My new knees (I feel like the Bionic Woman!) are allowing me new freedom to walk without pain. I don't take this feeling for granted. Is this the silver lining of adversity, that we don't know what we have until we lose it?

It's sometimes hard to make sense of pain and suffering. But we need to continue to show up and participate to the best of our ability and take charge of our most powerful ally, our mind.

Look at what you can do instead of what you cannot do. One of my favorite sayings is, "When one door closes, another opens, but it is hell in the hallway!" I have to thank my friends and family for pushing me through that hall.

This holiday season, please be sure to give thanks to all the people who have helped you. Reach out to a fellow patient and share your story... and listen to his or her story. And most importantly, make a list of what you are grateful for, and remember to hang onto hope!

Chronically Yours,

Lori Hartwell

President & Founder of Renal Support Network

weKAN Live & Give is a publication of the Renal Support Network, a patient-run non-profit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

weKAN Patient Activists serve to mobilize, educate, motivate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another. Together we can make a difference.

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Fight Procrastination: Do it NOW!

by Sharon Pahlka, weKAN Patient Activist

I procrastinate. Do you?

Let's *stop*.

Dreading something often takes more energy than doing it. There is a basic reason why most people don't accomplish what they could: They just can't get started. Why?

1. The task is difficult and/or overwhelming.
2. It is time-consuming.
3. We may lack knowledge or skills.
4. Fears.

Coaching Question

What will you do to eliminate procrastination?

Simple Cure

- ◆ Focus on getting started and developing momentum, not on finishing everything (perfectly).
- ◆ If the problem is lack of knowledge or skill, make a plan for getting more.
- ◆ Make a list of the benefits of not procrastinating.
- ◆ Identify your own goals, strengths, values, and priorities, and work within those.
- ◆ Compare your actions with the values you feel you have. Are your values consistent with your actions?
- ◆ Discipline yourself to use time wisely: Set priorities. (Remember, it's not procrastination if it wasn't worth doing in the first place.)

Procrastination is the thief of time.

—Anon

And if not now, when?

—Talmud

- ◆ Use the “inchworm technique.” Look at a project and break it into small chunks and work on the little pieces. Reward yourself after you complete a task, however small.
- ◆ Motivate yourself: Dwell on success, not on failure. Tell yourself: This isn't so hard, it won't take long, I can easily do some part of it, or I'll learn while doing.
- ◆ Picture in your mind what you would like to achieve. When

you have that clearly in mind, then begin somewhere—anywhere—trying to achieve some of your vision.

Coaching Tip

Overcoming

procrastination produces peace of mind, a feeling of being in charge of your life. You will experience increased personal freedom, so start working on procrastination today.

Homework

Make a list of five top procrastinations. Work on one each week. Pick a new one when you have that one done.

Resources:

Burka, Jane B. and Yuen, Lenora M. Procrastination. Reading, PA: Addison-Wesley, 1983.

Ellis, Albert and Knaus, William J. Overcoming Procrastination. New York: Signet Books, 1977.

2006 Renal Teen Prom

Continued from page 1

night to remember. Attendees will soon discover that one friend *can* make a difference!

If you are a teen or young adult with kidney disease (pre-dialysis, dialysis, or transplant), or you know someone who is, contact the Renal Support Network for an invitation to the prom.

As Plato wrote: “Music gives a soul to the universe, wings to the mind, flight to the imagination, and life to everything.”

The Kidney Care Quality and Improvement Act of 2005

120 Cosponsors in the House

19 Cosponsors in the Senate

Write and encourage your senators and representatives to support this bill. See a sample letter at RSNhope.org.

National Patient Meeting

Continued from page 1

the presenters spoke from their own experience as patients. “Health, Happiness & Hope” attendees came to Illinois from all parts of the United States, including California, Hawaii, New York, Washington state, and Arkansas, along with a strong contingent from the Midwest.

The weekend was full of opportunities to share information outside of the formal presentations and discussions. Special breaks, meals, and social events were planned to entertain and allow patients and professionals to talk with one another in a smaller setting. On Saturday night attendees enjoyed a dinner and magic show performed by Jamie Gilbert, otherwise known as Jamie-G, who had driven to Chicago from Canada after his dialysis treatment in order to entertain fellow patients. His performance was both fun and inspiring.

In a way, that is also how the entire weekend could be summarized – the sharing of information between patients and professionals in a fun and inspiring forum.

If you did not get a chance to attend the 2nd Annual RSN National Patient Meeting, we hope you will join us next year in Philadelphia, PA.

Save the date!

October 4 – 7, 2006



Malia Langen was diagnosed with kidney failure at age 13 and spent her teen years on dialysis. A kidney donated by her mother has kept her healthy for the past nine years. She enjoys helping young patients learn how to maintain life outside of the medical realm.



Sharon Pahlka has lived with kidney disease for over 30 years—19 years on dialysis and the last 11 years with a transplant from her brother. She is a Life Coach and speaker, specializing in coaching people with chronic health challenges. Check out her website at www.lifeisagift.com.

Difficulties mastered are opportunities won.

—Winston Churchill

HEALTH, HAPPINESS & HOPE

The 2nd Annual RSN National Patient Meeting

Held in Chicago, Illinois ♦ September 29 - October 1, 2005

See You Next Year!

**October 4 – 7, 2006
Philadelphia, PA**



A time to interact and make new friends.



I enjoyed every minute of the RSN National Patient Meeting. I learned something from all the speakers, but one session that I especially enjoyed was by Gail Wick, RN: "Leadership Pearls for Your Personal and Professional Lives." She started by saying: "Every one of us is a leader at life. Beware of the example you set for others to follow, for you will be followed." It was great!

- Sharon Pahlka, Washington



Even though I have been on dialysis for decades, I learned so many new things at the wonderful RSN National Patient Meeting, while also having fun! Jim and I were fascinated by all the speakers who had such great information for us. Above all, I was touched by the incredible people there—those with a passion for life who care about others. Thanks to all of you.

- Roanne F. Dale, Utah

It is always uplifting to be around other inspiring and motivated patients. That was my main reason for making the trip to Chicago, and the patients and professionals I met at the RSN National Patient Meeting exceeded my expectations. It reminded me once again that although we all have differing backgrounds and are unique individuals, we all share a similar story and a united goal to support one another and thrive in the face of kidney disease.

- Malia Langen, California



Words will never express my gratitude for the work of so few, which will affect so many.

- Bonita Balkcom Guilford, Georgia

Life has to be lived

That's all there is to it.

- Eleanor Roosevelt



Patients, friends, and spouses enjoy dancing to the live jazz ensemble at the Friday evening dinner.

I encourage every patient to go to a "Health, Happiness & Hope" conference if you have the chance. You will learn valuable information presented by professionals that are also patients, who have a first-hand knowledge of their topic. It is an experience you will not soon forget. I am already looking forward to next year!

- Heather Powell, Arkansas



Above: A panel of patients and physicians talk about various dialysis modalities.

Some of the excellent and informative speakers giving their presentations:

Right: Heather Powell, a transplant patient and licensed social worker, speaks about "Managing Stress in Your Everyday Life."

Middle: Donna Boswell helps us better understand the Medicare Prescription Drug Benefit.

Bottom: Dr. J. Michael Lazarus, Medical Director of Fresenius Medical Care, shares advice from personal experience about how to communicate with your physician.



From left:

Dr. Hamid Humayun and **Dr. Todd S. Ing**, nephrologists from Illinois.

Bill Peckham, on daily home hemodialysis.

Gia Dumas, on nocturnal in-center hemodialysis.

Julia Richardson, on nocturnal home hemodialysis (with her husband to her right).

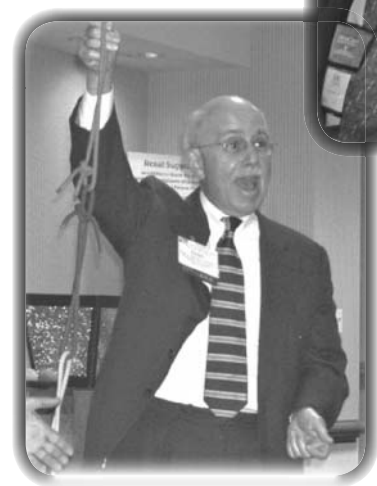
Jose Lagomasino, on continuous cycling peritoneal dialysis.



Jamie-G (Jamie Gilbert), Master Magician from Canada, entertains attendees on Friday evening. He receives some help from Tim Ryder of the Renal Support Network (left) and from a surprised Dolph Chianchiano of the National Kidney Foundation (bottom left). Lori Hartwell thanks Jamie for making the evening a success (below).

Thanks to the generous sponsors of the National Patient Meeting!

- Abbott Laboratories
- American Kidney Fund
- Aksys
- American Regent
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- Baxter Healthcare
- DaVita
- Fresenius Medical Care
- Genzyme
- iKidney.com
- NxStage Medical
- Sigma-Tau Pharmaceuticals
- Watson Pharma



A kind heart is a fountain of gladness, making everything in its vicinity into smiles.

- Washington Irving

My most memorable moments were with the magicians: Jamie and his two associates. While we waited for her ride, Mrs. Moody of Chicago and I were shown by Jamie how to do a clever trick that I will never forget. It was wonderful to meet everyone and be inspired by their stories. I was helped by the speakers, who shared their stories, expertise, and encouragement.

- Mike Herrera, California



Planning for An Emergency: Tips for Kidney Patients

by Heather Powell, weKAN Activist

In a natural disaster, planning ahead could mean the difference between life and death for a kidney patient. Dialysis patients are especially at risk. You may have to miss one or more treatments, or you may not be able to dialyze at your usual clinic. Utilities may be down. Emergency rooms may be overburdened and short-staffed. Have a plan in place so you know exactly how, when, where, and what you are going to do. Here are a few tips to help get you started.

1. Keep the following information with you at all times:
 - ✓ phone numbers: your dialysis clinic, doctors, and emergency contacts;
 - ✓ current list of medications: name, dose, and when each is taken;
 - ✓ medical history: diagnosis, surgeries, allergies, and other pertinent information.

2. Keep your Medicare number and medical insurance information with you.

3. Obtain a medical ID tag. This contains vital information about your medical condition and treatment, and alerts medical personnel to your special needs.

4. Ask a friend or relative in another area to be your designated contact person. In an emergency, you may not be able to make telephone calls within your immediate area, but may still be able to place calls to another area.

5. Stay home. If your house is not damaged and you are in no danger, this is the best place for you to be. You can always contact the police or emergency medical services if you need assistance.

6. Check in with your dialysis unit (and/or your doctor) so that they know where you are, and to find out if the unit is operating. Know your unit's emergency plan. If you have concerns about the plan, address them with your doctor and/or the clinic staff.

7. If your unit is not operating or if you are unable to reach the unit, you may be able to dialyze at a different unit. Make sure you have the names, locations, and phone numbers of back-up dialysis units and hospitals in your area. Many dialysis chains have toll-free numbers to help patients locate units at which to dialyze. Find out if your dialysis provider has a number to call and add it to your list.

8. Keep the following emergency supplies in a secure place:
 - ✓ battery-powered AM/FM radio and extra batteries (learn where on your radio dial to find the emergency broadcast radio station in your area, which will give you up-to-date information on current conditions and other emergency information even if you have no electricity or phone service)
 - ✓ flashlights with plenty of extra batteries, or candles and matches (remember, do not light a match until you have checked for natural gas leaks)
 - ✓ first aid kit
 - ✓ fire extinguisher
 - ✓ emergency phone list


9. Have an emergency plan with regard to meals in case you have to miss a treatment. Staying within your fluid and dietary restrictions is critical. Avoid foods high in potassium and sodium (see note below). CMS' booklet "Preparing for Emergencies: A Guide for People on Dialysis" has a detailed list you might find helpful regarding emergency supplies and food.

10. Be aware of all aspects of your dialysis prescription (hemodialysis or peritoneal dialysis). Your doctor or nurse can write out your prescription for you.

Hemodialysis patients:

- ✓ Keep an updated copy of your treatment flow sheet
- ✓ Know how often and how long you dialyze
- ✓ Know the basic settings of your machine and what size dialyzer is used
- ✓ Know your dry weight and how much fluid you usually gain between treatments
- ✓ Know what medications you receive during dialysis and the dose of each

PD patients:

- ✓ Keep on hand an extra week's supply of solution for manual exchanges
- ✓ Know how to do manual exchanges if you normally use a cyclor machine 

CMS offers a free booklet called "Preparing for Emergencies: A Guide for People on Dialysis."

Ask your dialysis unit for a free copy, or call 1-800-MEDICARE to obtain one. Ask for CMS Pub. No. 10150.

Go to www.medicalert.org/E-Health to find out about Medic Alert's new E-HealthKEY, a self-contained USB-enabled tool that stores your medical information and can be attached to your key ring.

IMPORTANT REMINDER ABOUT POTASSIUM

If your potassium level becomes too high, your heart could stop beating. This would be due to an electrolyte imbalance, which means that it could not be shocked into starting again. In other words, it has stopped forever. Therefore, staying away from an overload of potassium is critical!



Heather Powell celebrated her first anniversary with a transplant in October. She was diagnosed with kidney disease in 1982 at age eight, and has experienced all modes of dialysis including home hemo. During this time she also completed a BS in Psychology and a Masters in Social Work. She attributes all her successes in life to God's goodness and blessing.

Make the Most of Your Doctor Visit

by Bill Price, Ph.D., MSW, LICSW

I was diagnosed with irreversible acute renal failure on November 29, 1995, and started hemodialysis two days later. The diagnosis dealt a devastating blow to my psyche. My work, my hopes, and my ambitions suddenly were put on hold.

I had worked very hard toward achieving my Ph.D. in Social Work and received a series of promotions. I was on a fast career track. I felt confident and my life was full of meaning. Now I had to step back and take a life-assessment inventory of what this diagnosis meant for me and my future. I had to transfer all of my inquiry and research skills to learning more about my condition, dialysis, and strategies for coping.

My emotions were on a roller coaster. They twisted, turned, and vacillated among the various stages of grief: denial, anger, blame, bargaining (“God heal me and I will be a better person!”), depression, and, finally, acceptance. I had to stretch myself in order to wrap my mind around what was really happening to me, both emotionally and physically.

With a great deal of prayer and meditation, I accepted the reality of my condition and the fact that it was not going to go away. Only then was I able to reflect and take a proactive role in my treatment and care. I began searching for answers through reading and by asking questions of my doctor and medical team, and thus received the information I needed to make informed deci-

sions about my healthcare.

I have been on this journey now for nearly 10 years. From what I have learned, I recommend that anyone with a life-threatening health condition develop a collaborative partnership with his or her doctor and medical team. Let your doctor know that you want the best of care along with honest communication, and that you don’t want information withheld to “protect” you from the bad news.

Ask clear questions about your care. Between appointments, I would jot down questions as they came to mind. The night before my appointment, I would type out the questions I wanted the doctor to answer.

When I got to the appointment, I would hand the list of questions to my doctor and tell him I would like them answered at the end of the examination.

I had access to the University of Minnesota Bio-Medical Library and I would go there to read and make copies of journal articles so I could discuss what I had learned with my doctor. Frequently, I would give the doctor a copy of these articles for his files. I believe that the proactive approach I took toward learning about my condition and needs assured my doctor that I was a serious and active participant in my healthcare.

While you may not follow the exact recommendations I have made about communicating with your doctor, I hope they will encourage you to take an active role in your healthcare treatment as well.

.....
*Ask clear questions
 about your care.*



Potassium in a Typical Holiday Menu

(just one plateful!)

Roast Turkey - 3.5 oz.....	290
Bread Stuffing - ½ cup.....	90
Mashed Potatoes - ½ cup.....	300
Gravy - 2 oz.....	90
Sweet Potato Casserole - ½ cup.....	300
Winter Squash - ½ cup.....	350
Cranberry Sauce - ½ cup.....	40
Cranberry Orange Relish - ½ cup.....	50
Green Beans, Carrots, or Creamed Onions - ½ cup....	150
Cabbage - ½ cup.....	75
Pumpkin Bread - 1 slice.....	60
Pumpkin Pie - 1 slice.....	250
Whipped Cream - spoonful.....	15
Apple Cider - 4 oz.....	150
Gingerbread cookies - 6.....	300

TOTAL (mg): 2510

OTHER COMMON ITEMS

Apple Pie - 1 slice.....	120
Mincemeat Pie - 1 slice.....	330
Pecan Pie - 1 slice.....	150
Ice Cream - ½ cup.....	150
Fruitcake - 1 small piece.....	250

Note: Avoid anything with molasses. One tablespoon molasses = 300 mg potassium.

Potassium amounts are an approximation. Total potassium per food item derived from Bowes & Church’s Food Values of Portions Commonly Used, 17th edition, Jean A.T. Pennington (Ed.). ©1998 by Lippincott-Raven Publishers.

Holiday Eating

Continued from page 8

work well with your renal diet and that won’t leave you feeling like you’ve missed something.

For me, whether I am traveling for the holidays or entertaining at home, I still practice moderation. No one wants to be rushed to a medical facility due to over-indulging at a holiday meal, especially when away from home.

If you know your renal diet well, you can more easily choose foods that are safe to eat, or practice moderation if you choose restricted foods. Make life simple. Plan ahead so that you have a successful and enjoyable holiday season.



Bill Price is a retired school principal and independent clinical social worker. He lives in Minnesota where he is active as a volunteer in church, community, and kidney-related activities. In September 2000, he received a kidney transplant. After two years it rejected, and he now receives hemodialysis three times a week while awaiting a second transplant.

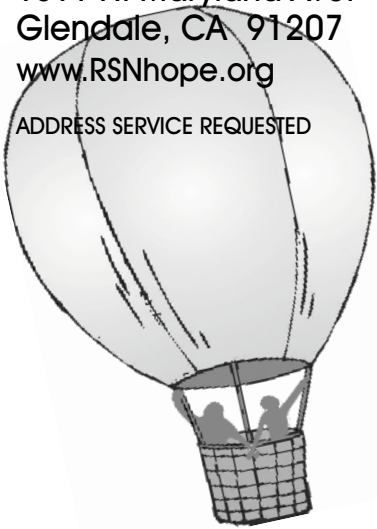


Jennifer Castillo has lived with kidney disease since 1979. During her years on dialysis, she completed undergraduate and graduate degrees while she also worked. She continues to incorporate dialysis into a life filled with work, ballroom dancing, and volunteer activities. She currently serves on the Editorial Advisory Board for Nephrology News & Issues.

The best way to cheer yourself up is to try to cheer somebody else up.

— Mark Twain

RSN relies on charitable contributions to support its many programs.
 Thank you for your help!



In this issue of Live & Give...
RSN National Patient Meeting Photos!

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ATTENTION

Did you pick up this newsletter in your dialysis center or transplant facility?

Sign up to receive your next issue at your home address.

Contact the Renal Support Network today!
(see page 2 for contact information)

To Your Health



Holiday Dining Tips

by Jennifer Castillo, weKAN Activist

Holiday Meals in Someone Else's Home

The best piece of advice when invited to someone's home for the holidays is to do your homework and plan ahead with regard to what you can eat.

If you are invited to the home of a family member or friend, you can talk to the cook about the menu ahead of time. You may not be the only person with special eating concerns. The cook really wants the entire meal to turn out perfectly for all the guests, so is usually more than willing to work with you to come up with an enjoyable and appropriate menu.

By speaking to the cook ahead of time, you may be able to bring your favorite dish with you or suggest some menu items that you know would fit into your diet and that others would enjoy as well.

Holiday Meals at a Restaurant

Once again, planning ahead can work in your favor. Find out what restaurants are in the area you will be traveling to. Often, you can call the restaurant ahead of time to learn more about their holiday dinner menu choices. You then have the option to ask the restaurant what possibilities there are for substitutions due to your dietary needs.

You could even ask if it would be okay to bring a special dish or drink to the restaurant to complement the meal because of a family member's dietary constraints.

An option for dessert may be to head back to your host's home instead of having dessert out. Once again, suggest desserts that would



*So much has been given to me,
I have not time to ponder over
that which has been denied.*

— Helen Keller

Calendar

Annual Renal Teen Prom

Music, Music, Music

Sunday, Jan. 15, 2006

Sherman Oaks, CA

3rd Annual RSN National Patient Meeting

Health, Happiness & Hope

Oct. 4 - Oct. 7, 2006

Philadelphia, PA

Thanks to our sponsors!



Fresenius Medical Care

