



#### KIDNEY KIDS Volunteer of the Year – 2006

Janie Wilner, pictured to the left, is KIDNEY KIDS Volunteer of the Year for 2006. As part of a Girl Scouts Honor Project, Janie decided to use \$100 of her own money to purchase materials to make jewelry, with the intent being to use the proceeds to purchase something for those in need. Through a friend, Janie learned about KIDNEY KIDS and decided she wanted to help INOVA's Pediatric Kidney Center. Not only did Janie purchase two game tables for the Pediatric Kidney Center waiting room, but she also held a book drive as well. Janie was so successful that she raised over \$1,200 and still has inventory left. She is going to sell the rest and purchase additional items for the Pediatric Kidney Center.

**THANK YOU AND CONGRATULATIONS JANIE!**

#### KIDNEY KIDS Blood Pressure Monitor Loaner Program

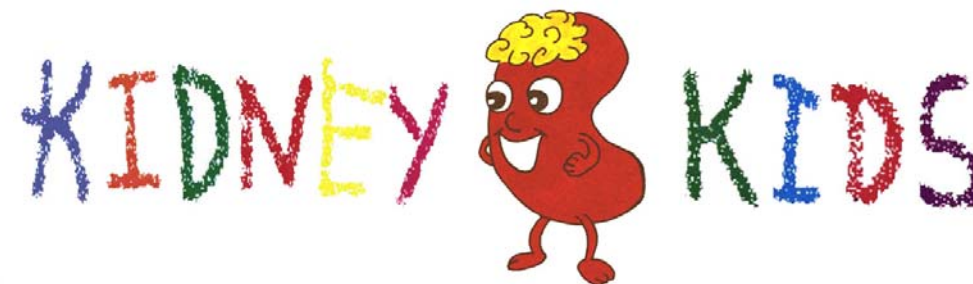
In August of 2004, KIDNEY KIDS purchased two GE Medical Systems Dinamap blood pressure monitoring machines to begin implementation of the KIDNEY KIDS Blood Pressure Monitor Loaner Program at INOVA's Pediatric Kidney Center. This equipment is loaned to families that are required to closely monitor their child's blood pressure to help determine the necessary medical protocol and appropriate medication levels. Previously, families would use the manual "blow-up" cuffs, which can be very inaccurate for the untrained and thus cause additional stress for the families. There has been such a need for these machines that in May of 2006, KIDNEY KIDS purchased two additional Dinamaps for the Pediatric Kidney Center. Pictured to the right is four month-old Alice, who was recently sent home with one of the KIDNEY KIDS Dinamaps.



The Board of Directors of KIDNEY KIDS are all volunteers. There are no paid staff.

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## NEWSLETTER

**"PROVIDING HELP AND HOPE UNTIL THE SEARCH FOR A CURE BECOMES A REALITY"**

#### KIDNEY KIDS, INC.

KIDNEY KIDS, Inc. is a non-profit 501(c)(3) organization devoted to supporting children with kidney diseases and illnesses as well as their families. We are striving to lessen the physical, emotional and financial impacts of living with a kidney disease or illness.

There are no cures for many kidney diseases. While no baby, child or family should ever have to endure this, many do. At a time when many medical researchers seek cures for these children's conditions, KIDNEY KIDS has a somewhat different goal – **to provide help and hope to these children and their families until the search for a cure becomes a reality.**

While many kidney diseases and illnesses are treatable or curable, many are not, and even those children with hopeful outcomes often must endure complex, sometimes risky treatment programs. There is still much work to be done despite the enormous progress thus far in treating childhood kidney diseases. In our D.C. metropolitan community alone, affected infants and children number in the thousands, and those who currently or imminently will require life-sustaining artificial kidney dialysis treatments and/or transplantation number in the *hundreds*.

Part of the mission of KIDNEY KIDS is to identify and provide access to educational, emotional and recreational resources and activities for children with kidney diseases and their families. Guidance is provided by the extensive pediatric kidney disease medical expertise that exists in our region. While need is a major factor, a high priority is placed on conventional and novel approaches focused on the nurturing of self-esteem and personal goals for the children, while helping families to succeed.

KIDNEY KIDS began its first-ever fundraising drive in March of 2004. We are very proud to report that, with your help, we have now raised over \$55,000 to support the work of KIDNEY KIDS.

**KIDNEY KIDS has no paid staff and 100% of your donations go to support KIDNEY KIDS programs.**

**THANK YOU FOR YOUR SUPPORT!**

#### KIDNEY KIDS Sponsors the Sixth Annual INOVA Pediatric Kidney Center Picnic

The INOVA Pediatric Kidney Center picnic was held on September 30<sup>th</sup> at Nottoway Park in Vienna. KIDNEY KIDS provided the picnic rental area, pony and horse rides, a face-painting clown, a moonbounce, food and prizes for all of the patients, their siblings and their parents, including Redskins and Nationals tickets, Ipod shuffles and Portable DVD players. All of the patients and their deserving families had a great time and we believe that this event has a very positive impact on those families in many ways. This is the third year that KIDNEY KIDS has sponsored this event.



Kaitlyn Turner with her Nephrologist Dr. Lynne Yao of INOVA's Pediatric Kidney Center.



Sidra, Mehdy, Taylor & Maryam look fantastic!

Dear kidney kids Thankyou  
for helping me to go to  
Camp Sunshine. It was a good  
investment. Camp Sunshine  
was one of the best camps  
and places I've ever been. I  
enjoyed it and I know my  
dad too, I want to go again  
please. Things we did were  
great. We went swimming,  
played game, lots of art's and  
crafts, and we had to make  
wish boats and we made  
jewelry cases. I want to go  
again and I hope you can  
help I would like that  
very much. Thankyou and  
you and your wife. God bless  
your family.  
Sincerely Adam Dunn



### KIDNEY KIDS Prescription Assistance Program

KIDNEY KIDS Prescription Assistance Program provides help to families of children with kidney diseases or illnesses by purchasing medications, supplements and necessary home-based medical equipment and supplies.

#### Here are just a few stories of how your donations have helped:

- “Gregory is a five year-old boy who has been on peritoneal dialysis for several years. He has suffered from failure to “thrive” but recently has turned the corner since introduction of Nepro (special formula) to his diet. Until now the Nepro has been provided, but he is aging out of the program. Gregory goes through six cases a month. The other complication is that Gregory’s dad was laid off right before the Holidays and has yet to find steady employment.” **KIDNEY KIDS provided 4 months of Nepro for Gregory.** “Gregory was recently added to the cadaveric kidney transplant list, so hopefully he won’t need Nepro for too much longer!”
- “Kimberly read in the local newspaper about the need for kidney donors and came forward to donate one of her kidneys to a teenage patient at Children’s National Medical Center who had been receiving chronic peritoneal dialysis. Kimberly thought that all of the related expenses would be covered by the recipient’s insurance, which is not the case for outpatient medications. She had to miss several weeks from work and finances had already been tight.” **KIDNEY KIDS purchased outpatient medications for Kimberly.**
- In May, two families ran into issues with the Medicare Part D program which resulted in their copayments not being covered for a period of time. These families ran out of medication for their children. All were single-parent families, with not enough income to cover the prescription copayments. **KIDNEY KIDS purchased all of the medications that the two boys needed until the Medicare program began coverage again.**
- “Mary is a four year-old girl who was diagnosed with nephrotic syndrome in May. She was hospitalized immediately and treated with high dose steroids and diuretics. Fortunately she responded very well. Her father did not have medical insurance and has since applied for Maryland Medical Assistance. Mary missed several follow-up appointments because her family was concerned about the mounting medical bills while they still did not have coverage. The medical team was concerned that Mary may relapse and wanted her parents to have urine testing strips, which can be used to monitor for that. Using urine testing strips the family will know when Mary needs medical treatment before it becomes an emergency with visible symptoms.” **KIDNEY KIDS purchased the urine testing strips for Mary.**

### Update On Other KIDNEY KIDS Activities

- For the third year, KIDNEY KIDS was the sponsor for the “Kids Corner” at the National Kidney Foundation of the National Capital Area’s (NKF) Annual Kidney Walk Fundraising event. KIDNEY KIDS distributed literature to those in attendance on pediatric kidney diseases and illnesses as well as KIDNEY KIDS Organ Donor cards. The kids were entertained with face painters, a magician, a balloon animal maker and other prizes and treats. The event raised over \$150,000 for the NKF.
- For the second year KIDNEY KIDS will be sponsoring the Children’s National Medical Center Annual Holiday Party. Last year KIDNEY KIDS gave iPod Shuffles and large stuffed animals to all of the pediatric dialysis patients.
- The KIDNEY KIDS website ([www.kidneykids.org](http://www.kidneykids.org)) is currently being redesigned. It is expected to be re-released in mid-January 2007 and will become a useful resource for families with children with kidney diseases or illnesses.

### KIDNEY KIDS Financial Assistance Program

KIDNEY KIDS Financial Assistance Program provides grants to families of children with kidney diseases or illnesses. These grants will assist in alleviating the financial burden placed on families as a result of treating and caring for a child with a kidney disease or illness. A significant burden can be placed upon families as a result of medical bills, medications, the frequency of treatment plans, necessary home-based medical equipment and supplies, as well as time away from work and lack of medical insurance.

#### Here are just a few stories of how your donations have helped:

- “Jonathan is an adorable 18-month old boy who was born prematurely and spent over a month in the neonatal intensive care unit. Unfortunately, Jonathan also had urinary reflux causing damage to his kidneys. He had multiple surgeries in early infancy but the scarring to his kidneys resulted in the need for chronic dialysis treatments. Jonathan was evaluated for a kidney transplant and the only major obstacle was his insurance coverage. Jonathan’s father does have medical insurance, however there are large co-pays and deductibles. Jonathan is eligible for Medicare, which will serve as secondary insurance, due to end-stage renal disease. Unfortunately, due to some unanticipated expenses, Jonathan’s family got behind on their Medicare premiums. The transplant team was very concerned about listing him without Medicare, because if he were to get a kidney, the family would have large out-of-pocket bills and ongoing expenses with his post transplant medications. The family had no ability to pay for the back premiums and the transplant surgeon wouldn’t transplant him until Jonathan had active Medicare because his family had such poor medication coverage through their private insurance” **KIDNEY KIDS paid for Jonathan’s back Medicare premiums.**
- Geoffrey is a young boy on dialysis. Last year his mother was fired from her job for using all of her medical leave to take her child to his regular dialysis treatments. It is very difficult for Geoffrey’s mother to work forty hours per week because she has to take Geoffrey to the hospital so often. **KIDNEY KIDS has twice paid for their rent and has also provided additional financial assistance.**
- “Paris is an 18 year old young man who receives peritoneal dialysis at Children’s National Medical Center. He has been maintained on dialysis since August of 2005 and is beginning the process to be listed for kidney transplant. He has had some urological complications which have delayed this plan. Paris elected to attend community college this year and hopes to be able to transfer to a 4-year school after two years. Paris is a friendly, sensitive young man who has done a tremendous job juggling his medical regimen, education, family responsibilities and social life. He lives with his mother who has multiple medical problems herself and will require surgery in the next few months. They struggle financially and unfortunately have not been connected with any government programs which may be able to assist. In the mean time, Paris happened to mention that he is having difficulty with math class because he has to copy the pages from a friend’s book. He did not have the money to buy the book right now.” **KIDNEY KIDS bought Paris his school book and provided additional financial support.**
- “Shawn has been receiving chronic dialysis for the last four years. Shawn’s mother works long hours while trying to meet his needs as well as those of his two older half-siblings. The idea of going on a vacation had never entered her mind given the financial constraints and Shawn’s dialysis regimen. Camp Sunshine in Casco, Maine is a free, family retreat for children and their families who are facing a chronic or life-threatening illness. The family’s car was to unreliable to make the trip. **KIDNEY KIDS rented Shawn’s family an SUV for the week and paid for all of the gas so his entire family could go to Camp Sunshine.**
- KIDNEY KIDS recently received an email from the social worker at Children’s National Medical Center that said the following: “At this time of year I always like to remember those who have had an impact on the children and families with whom I have worked – and say thank you! You and all of those affiliated with KIDNEY KIDS truly make a difference to this often forgotten pediatric patient population. Caring for a child with chronic kidney disease impacts so many areas of families’ lives for an extended period of time. What you are able to provide has helped some of these families avert crises situations, and as a result be in a better position to care for their child. Others have experienced a respite (Camp Sunshine) that they never would have had the opportunity to, without your organizations support. So I just wanted to say THANK YOU!”
- **THANK YOU FOR HELPING US HELP THESE CHILDREN AND THEIR FAMILIES!**

### MY SPECIAL CONTRIBUTION TO KIDNEY KIDS

*Financial support is vital to a local, volunteer-based organization like KIDNEY KIDS. Support us. You’ll be glad you did. We get things done!*

Enclosed is my gift of: \_\_\_\_\_\$25 \_\_\_\_\_\$50 \_\_\_\_\_\$75 \_\_\_\_\_\$100 \_\_\_\_\_Other

Name:

Address:

City:

State:

Zip:

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