

# 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 will be provided by the extensive pediatric kidney disease medical expertise that exists in our region. While need will be a major factor, a high priority will be 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 raised over \$45,000 to support the work of KIDNEY KIDS.

***THANK YOU FOR YOUR SUPPORT!***

## **KIDNEY KIDS Blood Pressure Monitor Loaner Program**



In the 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 Fairfax's Hospital for Children's Pediatric Kidney Center. This equipment will be 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. Please read the testimonial below to understand the impact this program is having already!

"Hello! Our son, Will, spent 2 weeks in the hospital recently where they found that he had severe hypertension. Before he started on BP medicine, his readings were 170's/120's. We are glad to say now that over the past 2 months his BP has dropped dramatically and is feeling wonderful.

Once released from the hospital, we knew we would be taking his BP every 6 hours and this was something we felt was going to be quite challenging...especially since we were given a manual cuff because that was the only thing they had for him, he was 7 months old at the time. The day we were supposed to be going home, the only person who could get a semi-accurate reading from our manual cuff was our doctor. Needless to say we were panicked and then our doctor remembered that KIDNEY KIDS had donated the Dynamap and she said we could take that home with us. We went to her office and tried it out and it was an instant success! We were so relieved and really could not have gone home if it wasn't for this WONDERFUL machine and your generosity. It has been a lifesaver and let Will come back to the comfort of his own home where his recovery has been a speedy one!

We cannot thank you enough and just wanted you to know that. Here is a picture of us right before taking his BP."

Sincerely - Amy, Brendan and Will

**UPDATE** -"Will is doing great and about to celebrate his first birthday. We are just so happy that he is progressing the way he is. It's looking like his problem has resolved itself, but we'll find out for sure when he gets a little older and they can go in and take a look at his kidney. In the meantime, the BP machine puts our minds at ease! What you are doing is a wonderful thing."

**“KIDNEY KIDS Partners With The Starlight Children’s Foundation To Help Make Kids Smile”**



In October of 2004, KIDNEY KIDS purchased two “Fun Centers” from the Starlight Children’s Foundation and had them placed at Inova Fairfax Hospital for Children’s Pediatric Kidney Center and the Children’s National Medical Center – Pediatric Dialysis Unit (D.C. Children’s). The mobile, multi-media Fun Center units are one of the signature programs for the Starlight Foundation. These brightly colored, mobile entertainment units contain a TV, VCR and Nintendo 64 game system in an irresistible enclosure that rolls right above the bed of a hospitalized child.

While entertainment is the prime focus of the program, its effects are far-reaching. Hospitals report that they frequently rely on “Fun Centers” to divert children during long hours of dialysis or treatments, and further, find that when children utilize “Fun Centers” during post-op their requirement for pain medication is reduced. Often described as “life savers” during long waiting periods during treatments, Fun Centers also help alleviate feelings of loneliness and boredom for children.

**“KIDNEY KIDS Sponsors Research Program For Inova Fairfax’s Pediatric Kidney Center”**

KIDNEY KIDS is proud to announce that it has recently funded an Ambulatory Blood Pressure Monitoring (ABPM) in Children research program for Inova Fairfax’s Pediatric Kidney Center.

Pediatric patients with borderline or liable hypertension may, at times, be over treated. In fact, the risks of treatment in those with mild hypertension have received emphasis in recent literature. ABPM provides a cost-effective approach to distinguish those who truly need therapy from those who do not, and can spare those who do not from unnecessary risks.

ABPM provides a fully automated measurement of blood pressure taken at frequent, programmable intervals during a 24-hour period. A battery-operated lightweight device is attached to the patient, who keeps a diary of their activities, symptoms, observations, and medications for correlation with blood pressure readings. **Avoidance of costly evaluations and inappropriate therapies for diagnoses exclusively based on casual, office-based measurement of blood pressure can be avoided.** In addition to the evaluation of suspected hypertension in children, the Pediatric Kidney Center anticipates significant potential for clinical research in their patients with CKD/End Stage Renal Disease receiving peritoneal or hemodialysis.

KIDNEY KIDS is very excited to be supporting this program!

**KIDNEY KIDS new mailing address as of 9/1/05**  
**KIDNEY KIDS**  
**10855 Weisiger Lane**  
**Oakton, VA 22124**

**Financial Assistance**

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.

Just recently, KIDNEY KIDS provided financial assistance to two families from D.C. Children’s Dialysis unit. KIDNEY KIDS began paying the prescription co-payments for medications for a young boy undergoing dialysis whose family is struggling with the financial burden of his continuing treatment. KIDNEY KIDS also paid for the travel expenses for a family of a boy who has undergone a kidney transplant so that his entire family could travel to a special needs camp in Maine.

**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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