

# weKAN and we DID!

by Lori Hartwell, weKAN President



One of my favorite Chinese proverbs is, "Tell me and I'll forget, show me and I may remember, but involve me and I'll understand." This quote is a roadmap to patient involvement.

Mapping out the plan for weKAN "patient activists" to visit Capitol Hill was a first-time experience for Renal Support Network (RSN). Knowing it was imperative to involve these intelligent patients in the process, RSN scheduled interactive conference calls to provide a forum for questions and input. The training materials created from this information would help patients become successful as effective spokespersons and advocates on behalf of fellow kidney patients.

The goal was simple – for each patient to make a personal connection with his or her elected officials and to

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**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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enjoy the experience. In addition, we aimed to give the patients the tools they needed to succeed in advocating for the Kidney Care Quality and Improvement Act of 2005 on Capitol Hill. Ultimately, we wanted more members of Congress to cosponsor the bill.

Scheduling an appointment and meeting with members of the U.S. Congress can be intimidating to most, but long-term kidney patients already have the skills to be effective advocates. After all, they have had to learn how to be persistent when talking to busy doctors, or when navigating complex insurance issues.

The weKAN patient activists are a very special group of individuals; many of them took time off from work or left their families to make the trek to DC. They are a volunteer "sales force."

As I reflect back on my days as a sales manager, I remember how imperative it was that I believe in and understand my product. Otherwise, the results could be disastrous. After a difficult sales meeting I would feel defeated, upset that I had not done my best.

It was also imperative that I involve the customer – in this case, the elected official. Real-life demonstrations generate interest. One of the patient activists on peritoneal dialysis explained that there is a special solution in her peritoneal cavity, and she was dialyzing at that moment. Another patient activist showed her dialysis access, a fistula, and informed the legislator that this was her "lifeline."

At the time of this printing, the Kidney Care Quality and Improvement Act of 2005 has 90 cosponsors in the House of

Lori Hartwell looks on as Jennifer Castillo shows her dialysis access to Paul Mitchell, legislative aide to Senator Boxer of California.



Representatives and 11 cosponsors in the Senate. If you want to learn more about H.R. 1298 and S. 635, keep reading this issue of Live & Give! For more information, visit our website at [www.renalnetwork.org](http://www.renalnetwork.org).

I encourage you to get to know your elected officials so that they can understand the needs of kidney patients by learning about you. If you would like to contact them, either in writing or in person, and need assistance, give us a call. We would be delighted to help you!

Since I began with a quote, it seems appropriate for me to end with a poem that epitomizes our organizational philosophy:

Did is a word of achievement  
Won't is a word of retreat  
Might is a word of bereavement  
Can't is a word of defeat  
Ought is a word of duty  
Try is a word each hour  
Will is a word of beauty  
Can is a word of power

– Anonymous

Chronically Yours,

Lori Hartwell

President and Founder of Renal Support Network

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**Do you know a patient who is making a difference in the lives of other patients? Please tell us! We may feature that person in an upcoming issue of Live & Give.**