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# PAC *Speaks*

A NEWSLETTER FOR PATIENT ADVISORY COMMITTEE REPRESENTATIVES

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Nocturnal Dialysis

## What's Your Nocturnal Dialysis IQ?

By Michael Butler, LAN SME, PAC Rep. Southern Manhattan Dialysis

There are more than 16 thousand patients receiving dialysis in the New York metropolitan area but only 10 extremely fortunate individuals can say that they are in-center nocturnal participants, and I am one of them.

At my center, in-center nocturnal dialysis programs usually occur in the overnight time frame from 7 to 8 hours, 3 times per week.



**Michael Butler**, LAN SME,  
PAC Kidney School planning  
committee, PAC Rep,  
S. Manhattan Dialysis

I started dialysis in 2009  
and in 2011 became a PAC  
Rep working to improve  
communication and

conditions at my facility between onsite  
management and the patients they serve.

Since then, I have become an advocate, a  
LAN Subject Matter Expert, and a founding  
member of the PAC Kidney School  
program. I enjoy working with others to  
achieve their best health while living with  
ESRD. Whenever I travel, I look for  
nocturnal dialysis programs. I have received  
standard treatments in Tobago and Puerto  
Rico, but have been lucky enough to  
receive excellent in center nocturnal  
treatments in Milford, Connecticut, and have  
visited a nocturnal program in San Diego,  
California.

We are all on this journey together. There  
are a lot of improvements to be made, and a  
lot of information to be shared. Let's make it  
happen, together.

In 2009, for first few months of my dialysis history I had difficulty meeting the goals of my healthcare team. The short regular in center 4 hour treatments 3 times weekly was never enough for me, unless I could adapt to a high flow rate in the range of 400-450 ml/min. That rate wasn't sustainable for me, because with my history of very high blood pressure with rapid development of congestive heart failure I needed a kinder and gentler form of dialysis to achieve the type of balance that my 6 foot 2 inch mid-century body could handle.

Fortunately for me, my healthcare team recognized my struggle and offered me a gentler and more therapeutic form of dialysis with fewer side effects called "nocturnal dialysis". In center nocturnal dialysis became my preferred treatment modality. This extended time frame of dialysis with dramatically slower flow rates has, over time allowed me to reduce my meds for blood pressure control and improve the functionality of my heart. I am thriving now instead of surviving.

For any dialysis patient trying to navigate their way to the best treatment modality for themselves, there are lots of pros and cons to figure out. But

know this; outside of a kidney transplant, the only way to achieve better fluid and toxin removal is some form of extended time dialysis treatment<sup>1</sup>.

For now, if you live in Manhattan, you have only one facility that offers in center nocturnal dialysis, Southern Manhattan Dialysis. Located on 6th Ave between 13th & 14th Street, it is a 26 chair, open layout facility in the basement of the building. I've heard it called the "crown jewel" of dialysis centers because, of the uniqueness of having the only nocturnal program available to the ESRD community in Manhattan.

Nocturnal dialysis as a preferred treatment modality is clearly not for everyone, but for me and nine other participants, it is a life sustaining intervention that really works for us.

## **RESOURCES:**

Nocturnal dialysis just might be your new best treatment modality. To explore more about this healthcare option, you can contact the Network to find in-center nocturnal dialysis programs or look at the following:

### **AAKP: Nocturnal Dialysis Offers Better Health While You Sleep**

<https://www.aakp.org/education/resourcelibrary/dialysis-resources/item/nocturnal-dialysis-offers-better-health-while-you-sleep.html>

### **DaVita Nocturnal Programs:**

<http://www.davita.com/services/in-center-nocturnal-dialysis>

1-866-994-SLEEP (1-866-994-7533)

### **Fresenius Nocturnal Programs:**

<http://www.ultracare-dialysis.com/FreseniusMedicalServices/NocturnalDialysis.aspx>

Call 866 254-3639

### **In-Center Nocturnal Dialysis Facilities in NY State:\***

Bedford Park Dialysis Center (DaVita)	(718) 920-1530	Bronx
H & L Ruben Dialysis Center (DCI)	(518) 587-1919	Saratoga Springs
S. Manhattan Dialysis Center (FMC)	(212) 675-6880	New York
Strong Health Dialysis-Brighton (FMC)	(585) 273-7600	Rochester
Yonkers Dialysis Center (DaVita)	(914) 377-2370	Yonkers

*\*list as of 3/31/2015*

To file a grievance, please contact:

End-Stage Renal Disease Network of New York 1979 Marcus Avenue, Lake Success, NY 11042-1072

Main: (516) 209-5578 Patient Toll-Free: (800) 238-3773 Fax: (516) 326-8929 E-mail: [info@nw2.esrd.net](mailto:info@nw2.esrd.net)

[www.esrdny.ipro.org](http://www.esrdny.ipro.org)

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<sup>1</sup> Nephrol Dial Transplant. 2009 Sep;24(9):2915-9. doi: 10.1093/ndt/gfp295. Epub 2009 Jul 7. Survival among nocturnal home haemodialysis patients compared to kidney transplant recipients. <http://www.ncbi.nlm.nih.gov/pubmed/19584107/>