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Dear CRIC Participants,

As you may already know from the previous newsletter, the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) at the National Institutes of Health (NIH), has extended funding for the CRIC study for another 5 years! Re-enrollment for CRIC Phase IV has begun. From 2003, the CRIC Study has successfully recruited and followed a study population of almost 5000 participants with chronic kidney disease. As shown in the figure to the left, 81.9% of participants from CRIC Phase I-III have already re-enrolled in CRIC Phase IV. Some of these participants have been in the study for more than 15 years!

During this phase, we will not only continue to follow our current participants but will offer novel ways to collect additional data from home using mobile technology and wearable devices. The investigators and coordinators at the CRIC Study Center where you are followed will be able to provide you with details about the new activities in CRIC Phase IV.

*“The success of the CRIC Study is a reflection of your longstanding commitment, we are greatly appreciative”*

I would also like to take this time opportunity to thank you for your continued participation in the study. The success of the CRIC Study is a reflection of your longstanding commitment, and we are greatly appreciative.

In this issue, we have provided you with participant testimonials, summary of a publication from CRIC, an article on the importance of the caregiver and a word search activity.

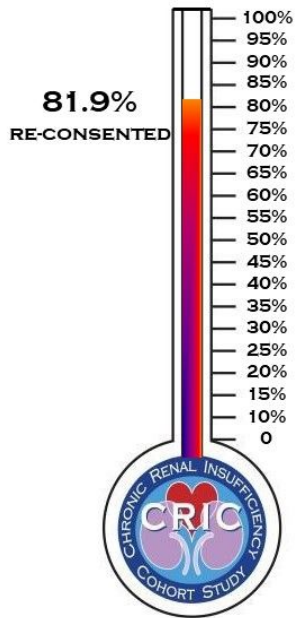
If you have any questions or comments about CRIC or about this newsletter, please do let us know. Once again, many, many thanks for your partnership in this critical study and your commitment to helping fight kidney disease.

Wishing you and your families a safe and enjoyable summer.

Warm regards,

Harold I. Feldman, MD, MSCE

CRIC CHRONIC RENAL INSUFFICIENCY COHORT STUDY  
CRIC RECONSENTED



NIDDK



## Attention CRIC study participants, we want to hear from you!



Your time and commitment to the CRIC study have been invaluable. As you know, the CRIC study began its fourth phase that will take us all the way to 2023! We are exploring new ways of incorporating a patient and caregiver perspective into the conduct of the study by creating a Study Participant Advisory Board (SPAB). Members of the Board will speak regularly with the study's researchers to provide their opinions, describe their experiences, and make recommendations. We are looking for current participants and/or their caregivers to sit down and discuss their experience with us at a local focus group conversation on topics such as:

- ✓ What are **your favorite** (and least favorite) parts of a CRIC visit?
- ✓ What has been **most valuable** to you as a participant?
- ✓ What has been **most challenging** about making it to visits?
- ✓ What do you **wish** CRIC or another study could tell you about kidney disease?


While we cannot promise to incorporate your feedback, we value your experience and want to make sure that your voice is heard! If you or a loved one are interested in sharing your CRIC experience, please contact your local CRIC study coordinator to let them know you are interested and find out site specific details.

## PARTICIPANT TESTIMONIAL

### Can you please give me a brief description about your experience wearing the zephyr biomodule?

*CRIC Participant (JW): It was very easy to do. It did not disturb my sleep. The changing and charging of the device was very **easy**. It was a **pleasure** to participate. Some research stuff you don't want to do but this was very easy and it gave me a lot of **good information** to give to my doctor.*

### What prompted your interest to participate in the Zephyr substudy?

*CRIC Participant (JW): Some studies you know  are going to help a lot of people in many ways all around and I thought this is one of them. Also, it sounded **fascinating**. I wanted to know the information about my own self.*

### Can you list some benefits from participating in the Zephyr substudy?

*CRIC Participant (JW): The main benefit is the information that was provided to me. Another **benefit** of participating is knowing that I am helping other people.*

### What has been the most positive experience of your continued participation in the CRIC study?

*CRIC Participant (JW): The staff, you have the **best staff!** The staff is very friendly and warm. I know I am a hard stick for blood draws. They know when I am coming in for a visit and they get me ready and all set up. The staff is **warm** and **friendly** and it makes you want to come out and help with the study.*



## Urinary Oxalate Excretion and the Risk of Chronic Kidney Disease Progression: Findings from the CRIC Study-JAMA Internal Medicine!

Oxalate is a small chemical found in food and also produced by the liver. It forms into a crystal with calcium. Calcium-oxalate stones are the most common types of kidney stones. Oxalate can also potentially damage the kidney. In rare forms of inherited diseases called primary hyperoxaluria, children develop kidney failure because their livers produce excessive amounts of oxalate. The best way to diagnose how much oxalate is being produced in the body or ingested from foods is to measure oxalate in 24h urine samples.

CRIC participants provided 24h urine samples that were used in a recent publication. Investigators at BWH and CRIC measured the 24h urine excretion of oxalate in CRIC participants and asked whether higher

levels were associated with an increased risk of kidney disease progression. They found that this was in fact the case: people who had the highest levels (top 20%) of urine oxalate had a 45% higher risk of developing kidney failure than people in the lowest levels (bottom 20%) of urine oxalate.

The significance of these findings need to be further studied.

Association of Urinary Oxalate Excretion with the Risk of Chronic Kidney Disease Progression. Waikar SS, Srivastava A, Palsson R, Shafi T, Hsu CY, Sharma K, Lash JP, Chen J, He J, Lieske J, Xie D, Zhang X, Feldman H, Curhan GC Chronic Renal Insufficiency Cohort study investigators. JAMA Intern Med. 2019 Mar 4. doi: 10.1001/jamainternmed.2018.7980.

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## Five Ways to Care for the Caregiver

The title of caregiver may be honorable and heroic, but it can come with a lot of responsibilities and pressure. Some caregivers may feel underappreciated or under-recognized. Many caregivers also have paid jobs in addition to the time they spend helping a friend or loved one. No matter how much time one spends in the caregiver or carepartner role, a commonality is that they often dedicate so much time caring for others that they forget to care for themselves. We're here to support you! Here are the **National Kidney Foundation's Top 5 Tips for Caring for the Caregiver.**

### 1 Set aside "me" time

Everyone deserves time for themselves and there's no need to feel guilty about it. It's important to establish boundaries and to designate this time for yourself. Carve out "me" time in your calendar to do something you find relaxing, whether it is spent reading, at the gym, or listening to music. This time allows you to decompress and focus on your own needs.

### 2 Ask for help when you need it

Remember that you don't have to do it all. Others may be willing to help but may not know how. Speak up when you're in need and give people specific tasks to assist you, even if this just means letting someone else drive your loved one to an appointment. There are also many organizations that help with transportation, bathing and meals.

### 3 Relieve stress

Constant stress can take its toll on your health. To relieve stress, take a walk. Listen to music. Set aside time to relax or write in a journal. Everyone releases stress differently, but do what works for you.

### 4 Pay attention to your own health

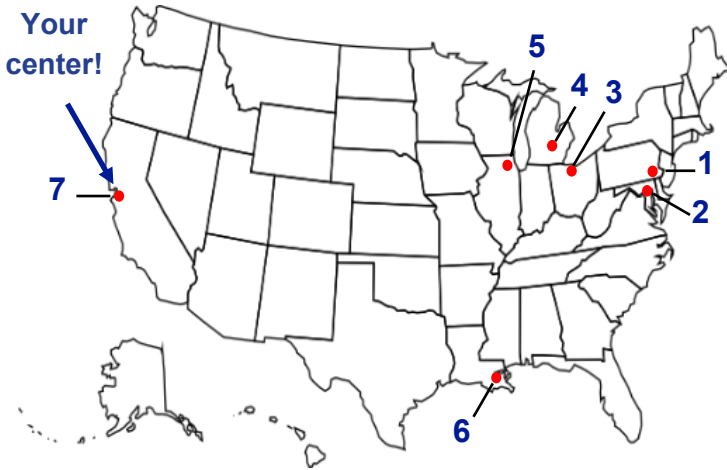
Caregivers aren't invincible. Don't take care of another's needs to the detriment of your own physical and emotional health. Listen to your body for cues. Eat meals sitting down rather than on the go, and aim to get 6-8 hours of sleep each night. Don't neglect seeing your own doctors just because you spend a lot of time at the doctors' offices of your loved one.

### 5 Connect with others who understand

Support groups that exist to connect caregivers with other caregivers. Some meet in person while others take place online or over the phone, forming a community of individuals who understand each other's needs. You can also speak with a friend, clergy member or therapist for more one-on-one support. You can call the NKF Cares Helpline toll-free at 1-855-NKF-Cares (653-2273) or email us at [nkfcares@kidney.org](mailto:nkfcares@kidney.org). Speak with a trained professional who will help answer your questions and listen to your concerns. You are not alone! Go to [www.kidney.org](http://www.kidney.org) for more information.



### CRIC Steering Committee



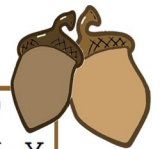
### Clinical Research Centers

- 01-01 University of Pennsylvania Medical Center
- 02-01 Johns Hopkins Medical Institutions
- 02-02 University of Maryland
- 03-02 University Hospitals of Cleveland
- 03-03 MetroHealth Medical Center
- 03-04 Cleveland Clinic Foundation
- 04-01 University of Michigan at Ann Arbor
- 04-02 St. John Health System/RRRI
- 04-03 Wayne State University/Detroit Medical Center
- 05-01 University of Illinois at Chicago
- 06-01 Tulane University Health Science Center
- 07-01 Kaiser Permanente of Northern California
- 07-02 University of California, San Francisco


### Autumn

#### WORD SEARCH

E	A	X	W	A	L	R	S	T	S	T	
T	K	W	Q	U	E	E	F	G	C	N	Y
F	B	O	O	T	S	F	A	E	I	D	L
H	A	E	A	R	C	I	L	S	K	A	I
M	F	E	O	E	A	P	L	S	C	S	E
A	W	H	H	E	P	U	M	P	K	I	N
S	I	H	K	A	R	B	E	T	P	R	D
E	A	A	N	E	Y	N	M	R	O	A	C
O	R	J	X	K	V	S	N	C	G	R	Q
H	L	E	A	F	S	C	A	R	F	I	O



- SCARF    APPLE    BOOTS
- TREE    FALL    RAKE
- ACORN    PUMPKIN    PIE
- HAY    SWEATER    LEAF

 We'd love to hear from you!

If you have any questions about the study, please feel free to call us.

Looking forward to seeing you again soon!