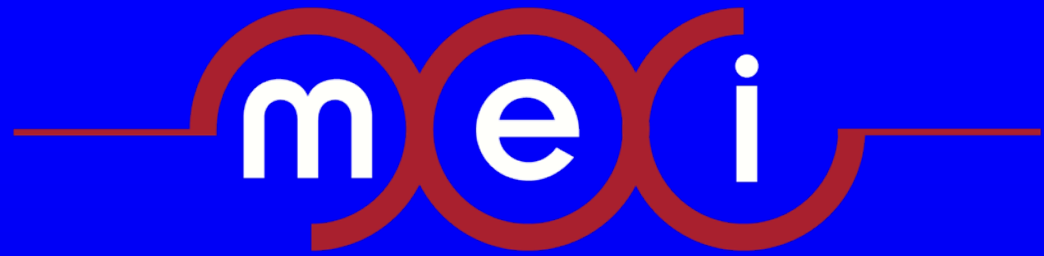


# **Social Media: Building and Using Electronic Media to Improve Communications with Patients**

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**Dori Schatell, MS**





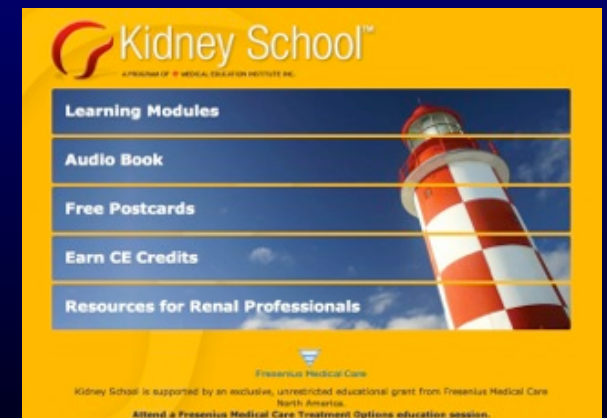
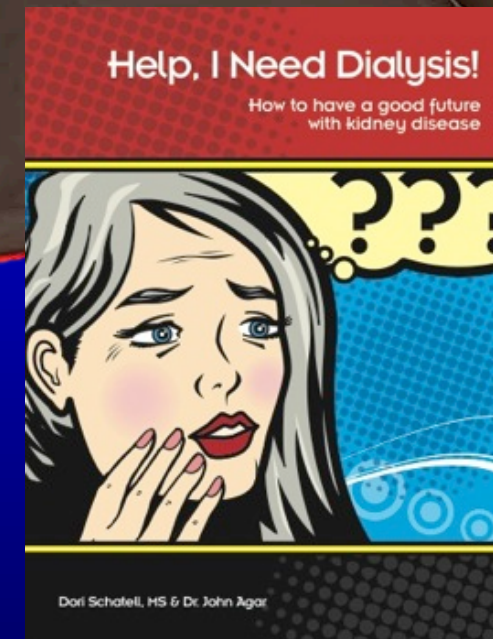
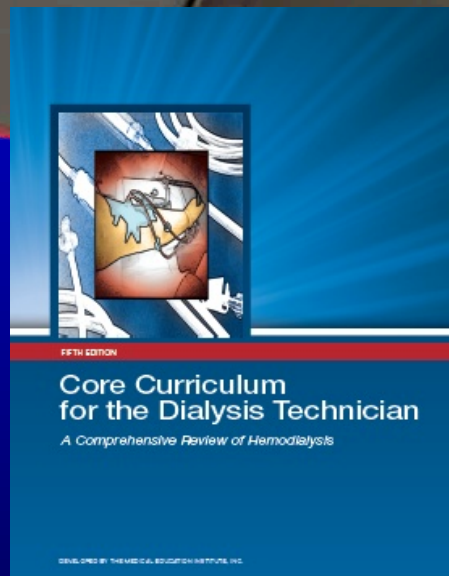
MEDICAL EDUCATION INSTITUTE

# Using Social Media to Engage Consumers

Dori Schatell, MS

Medical Education Institute 9/2/2014

★ MEI Mission: *Help people with chronic disease learn to manage and improve their health.*

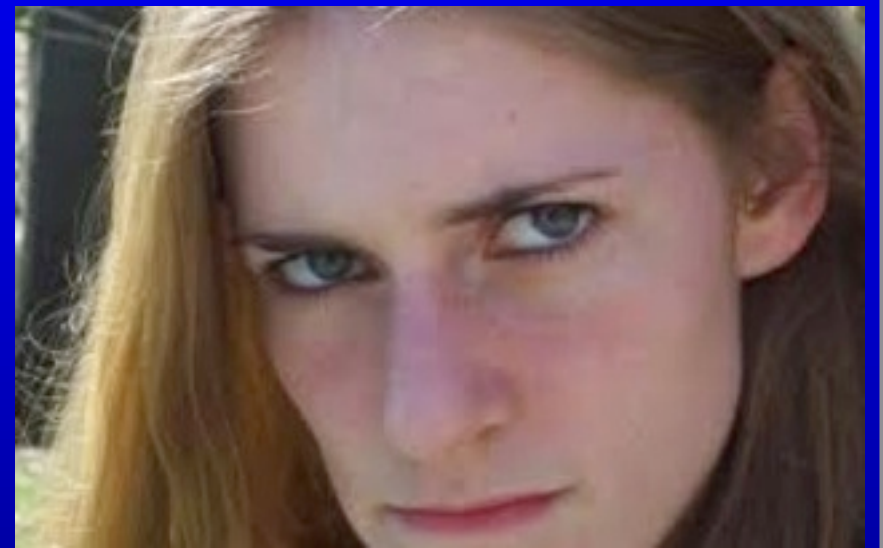






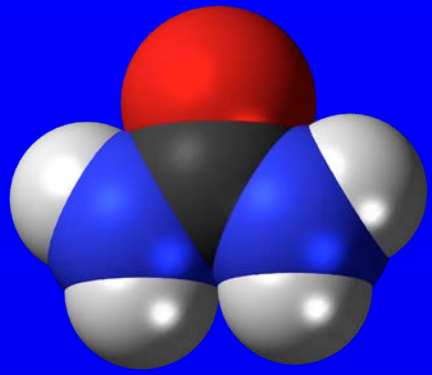
**KIDNEY DISEASE IS A TSUNAMI IN PEOPLE'S LIVES**



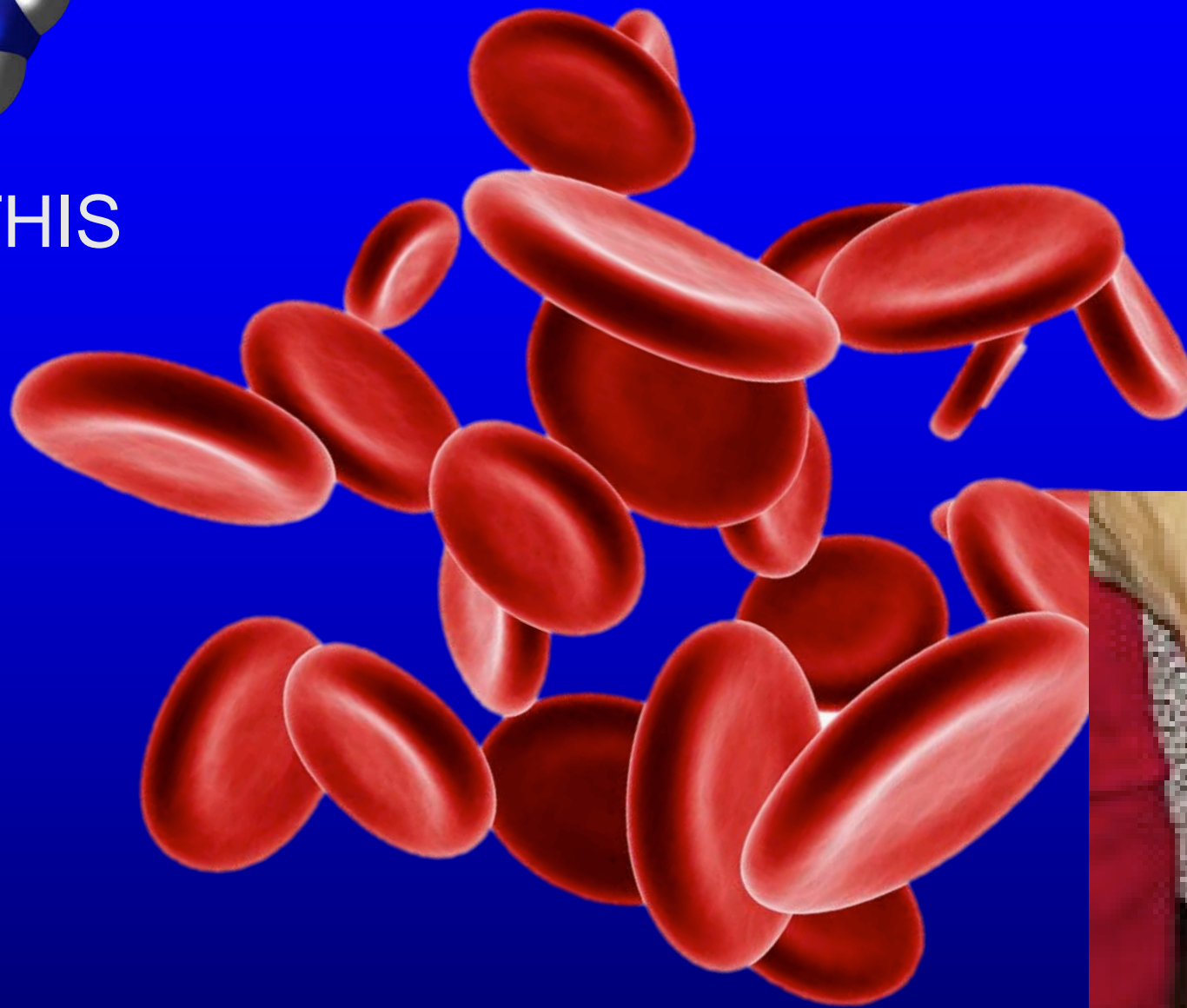


**STRONG EMOTIONS ARE NORMAL**  
TERROR, ANGER, DEPRESSION...





Remove THIS



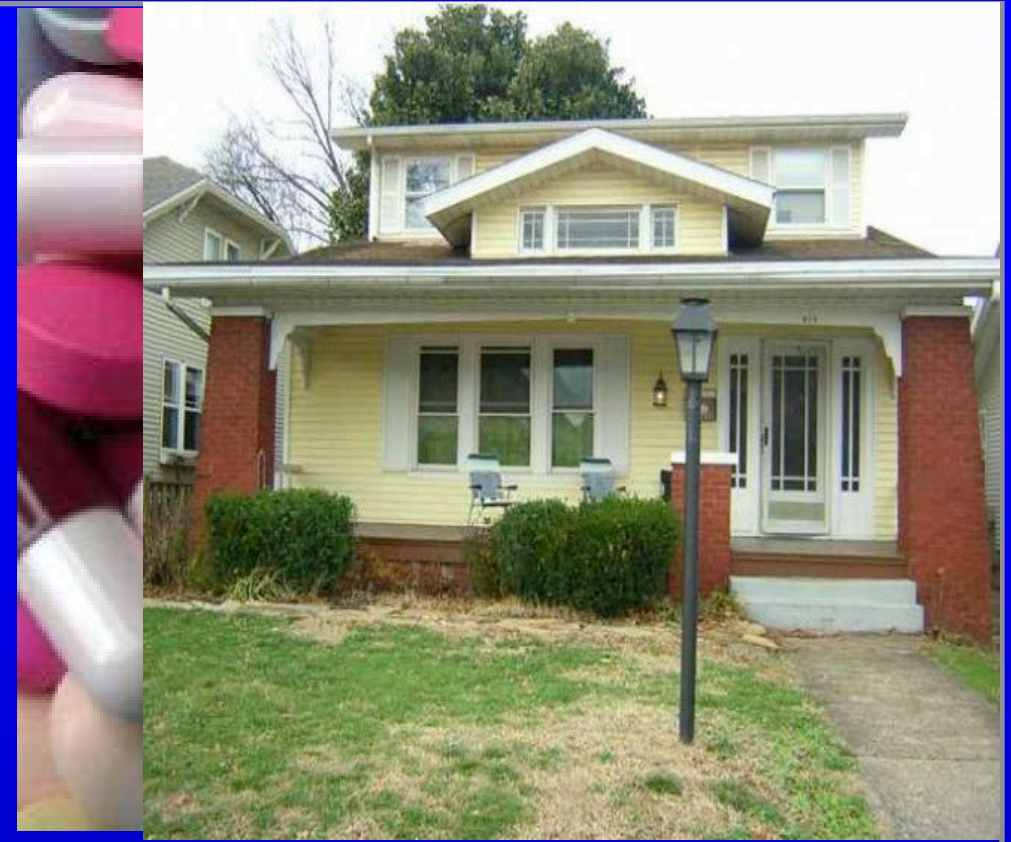
From THIS

Using THIS



WHAT WE FOCUS ON

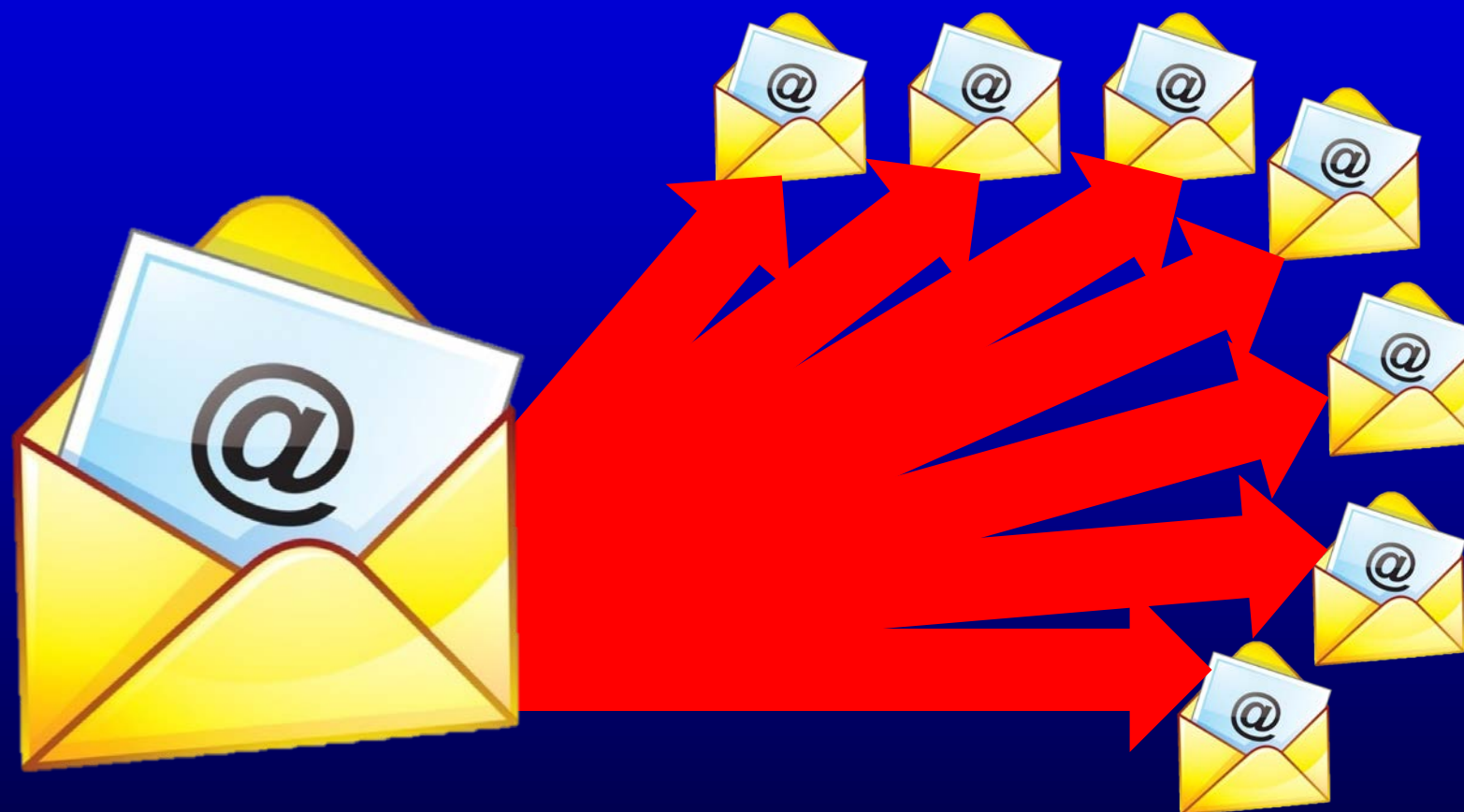
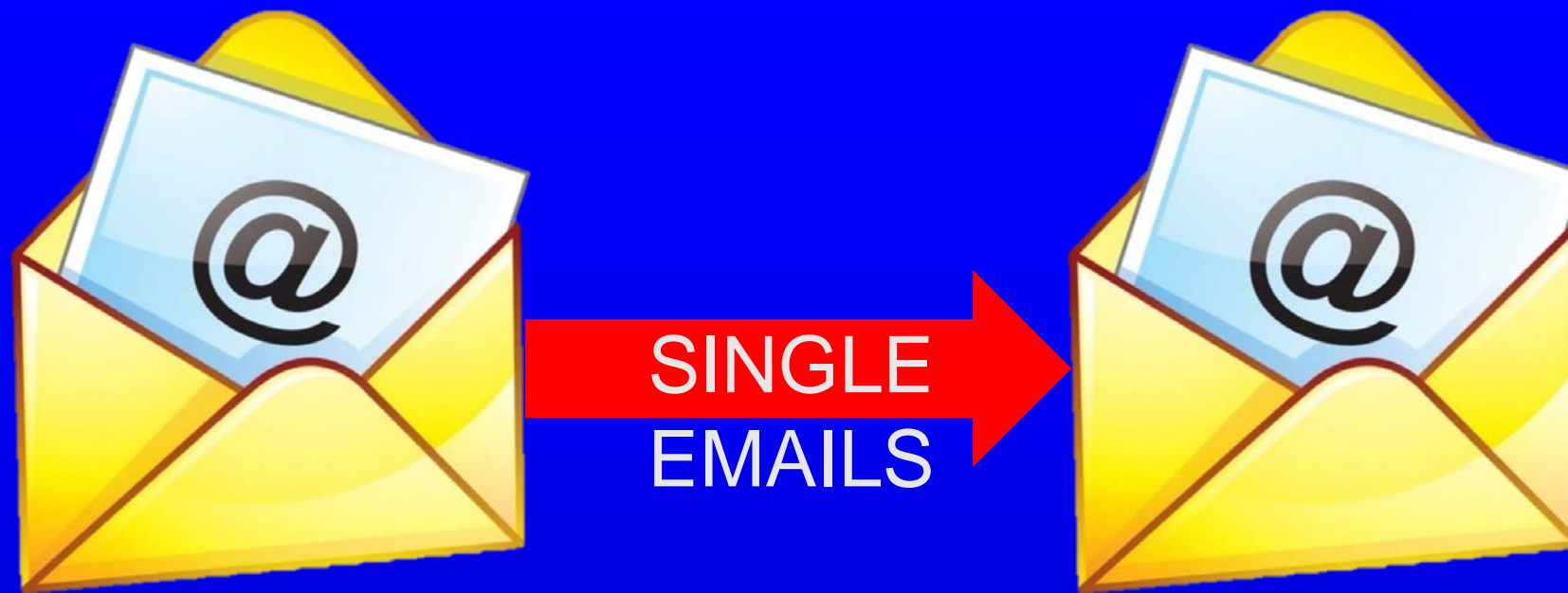
Other countries don't even bother to look at urea clearance



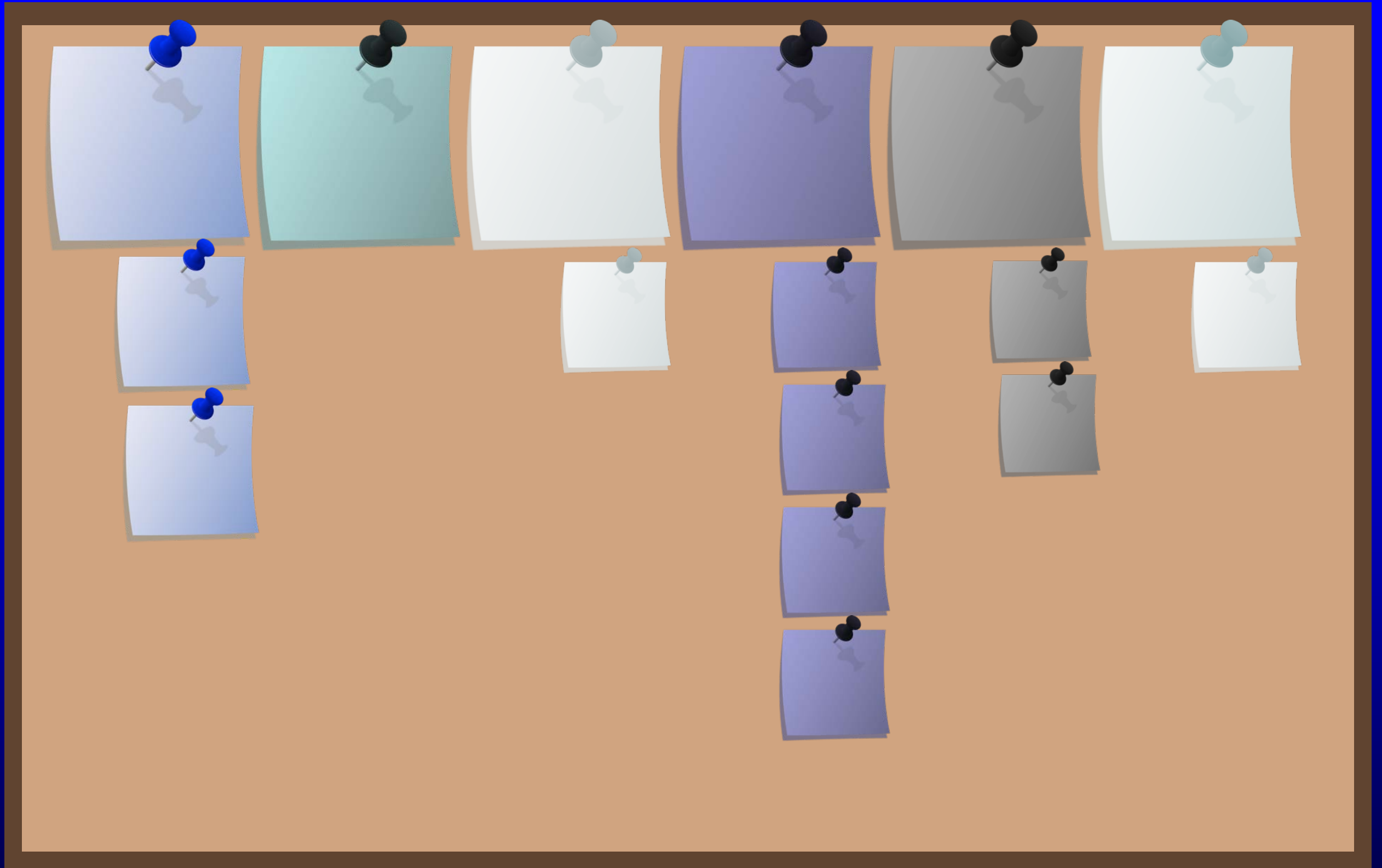
WHAT CONSUMERS FOCUS ON: THEIR *LIVES*

# Internet & Social Media





EMAIL & LISTSERVS – Early “Social” Media; Still in Use



MESSAGE BOARDS – SEARCHABLE, ENDURING





**Elaine**

Yesterday at 11:17

I see a lot of mention here about middle molecules and such. I feel so undereducated about my dialysis! I trusted my medical professionals to tell me what I needed to know, and I'm finding I know the bare minimum. Could someone point me to a good article that explains things like middle molecules and how everything works. I am reading everything I can get my hands on to be better informed. Thanks everyone.

Like · Comment

👍 5 people like this.

💬 View 8 more comments



**Dori Schatell** 😊

18 hrs · Like



**Elaine** I found Kidney School and have been going through that! It should be required for everyone newly diagnosed with CKD!!! I haven't ordered the book yet, but I plan to.

16 hrs · Like



**Elaine** thanks, again!

16 hrs · Like



**double your deals!**

5146.xg4ken.com

40% off your Gap purchase!



**Picture People**

picturepeople.com

Beautiful portraits printed in-studio the same day. This offer is for a limited time only!

Facebook Discussion Groups: Asynchronous, Temporary

# Chronic Disease & Internet Use

- ★ **51% of Americans have looked online re: health**
- ★ **Chronically ill less likely to be online (62% vs. 81%)**
- ★ **Issue: Lack of access, NOT lack of interest**
- ★ **Key activities: Blogging & online health discussions**



# Hearts In The Crossfire: Standard Hemodialysis Stuns Organs—But, There Is Hope!

This blog post was made by Dori Schatell, MS, Executive Director, Medical Education Institute on February 26th, 2015.



<b>Social Media Use (Observed)</b>	<b>Reason?</b>
Connect	Network
Learn	Frustration
Offer support	Advise
Find support	Validation
Observe	Understand

**PATIENT USES OF SOCIAL MEDIA**

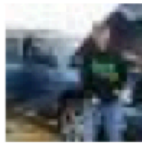


# What Can We Learn from Consumers?

## ★ How they feel from day to day

Question of the Day: 4/29/2013?

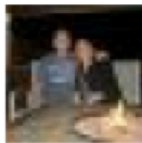
How many bad days do you have in one week? Ex: nausea, weak, fatigue, etc.



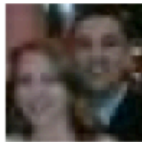
**Ken** every time i have a treatment



**Marie** Always weak and fatigued.. Nausea not so much anymore but it happens time to time



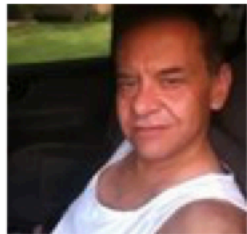
**Lisa** Normally no bad days.. He felt bad this morning but the machine pulled off .7 over the target last night, so that is why!



**Nancy** Every Monday, Wednesday and Friday for treatment days. I ache so bad all over and run a low grade fever. Nausea on and off.

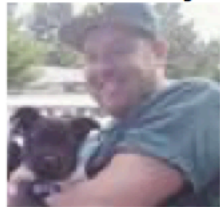
# What Can We Learn from Consumers?

## ★ What they worry about or fear

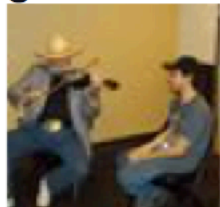


**Wally**

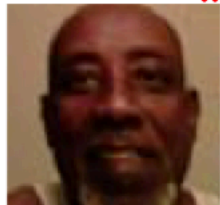
How many of you are, like myself, hesitant to travel because you don't want to leave your home dialysis center?



**Terry** I'm flying to so-Cal in June, and will only go for the weekend so I can get back to my center Monday. I understand your concern.



**Ned** Me me me



**William** I've never been afraid to travel. Most centers accept travel patients, & even cruises accept dialysis patients. Don't hold back! Enjoy the ride!

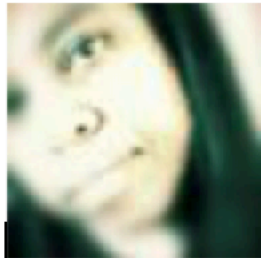


# What Can We Learn from Consumers?

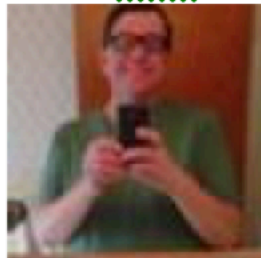
## ★ What bothers them

**Fran**

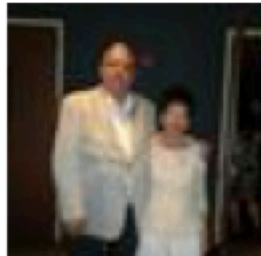
Some days I feel like dialysis would be bearable if I didn't have a fluid restriction. This is truly what I struggle with the most especially on the weekends when I'm hot and all I really want to do is chug a giant glass of ice water.



**Beth** So true! Its hard to keep it under, or right at 32 oz.



**Kevin** fluid limit is the hardest thing for me being on dialysis.



**Kayla** I feel the same way.

# What Can We Learn from Consumers?

## ★ What sort of support they have (or want)



**Wilma** I would like my family and friends to acknowledge the fact that I have been dealing with ESRD and dialysis for two years now. I would like someone to ask me how I'm doing, maybe come by and see me while I'm doing dialysis (it isn't contagious!!!). It seems like out of sight, out of mind. I'm not asking for it all to be about me, me, me, but at least a little acknowledgement here and there would be nice.



**Charles** I think some sort of acknowledgement of what has happened. I've seen NO ONE (Family) in 11 months since I started tests for transplant and of course the start of dialysis???????

# Suggestions for Social Media Observers

- ★ Follow P&P re: “Friending” posting





# Suggestions for Social Media Observers

★ Show R.E.S.P.E.C.T.



# Suggestions for Social Media Observers

✦ Disengage



**KEEP  
CALM**

**AND**

**DON'T TAKE IT  
PERSONALLY**

# Suggestions for Social Media Observers

- ★ Help with *questions*—beware of answers





★ **Prime the pump** – Ask questions to get things rolling

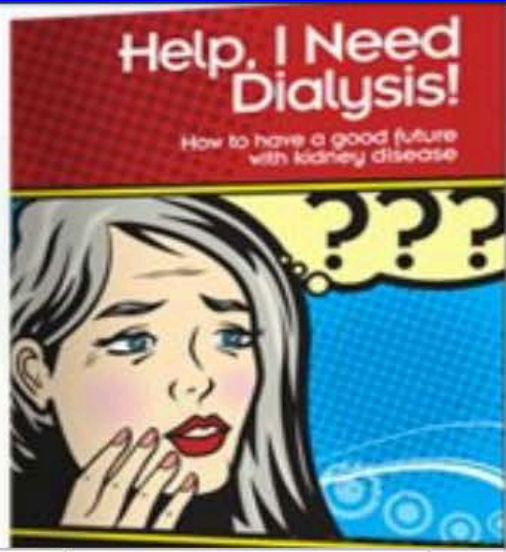


**STARTING A SITE? LESSONS LEARNED**

★ Zero tolerance for spam or bullying



STARTING A SITE? LESSONS LEARNED



Joined ▾ Share Notifications ...

Home Dialysis Central Disc... Members Events Photos Files Search this group

Member Requests 1

Reported Posts

Group Information

Member Requests Add All Ignore All



**Debera Sabado**

Joined Facebook less than 5 days ago  
Member of 0 groups

✓ Add × Ignore Block

STARTING A SITE? SPOT SPAMMERS





Debera Sabado

Add Friend Message

Timeline About Photos Friends More

Recent 2014 Born

DO YOU KNOW DEBERA?

misspelled name

To see what he shares with friends, send him a friend request.

Add Friend

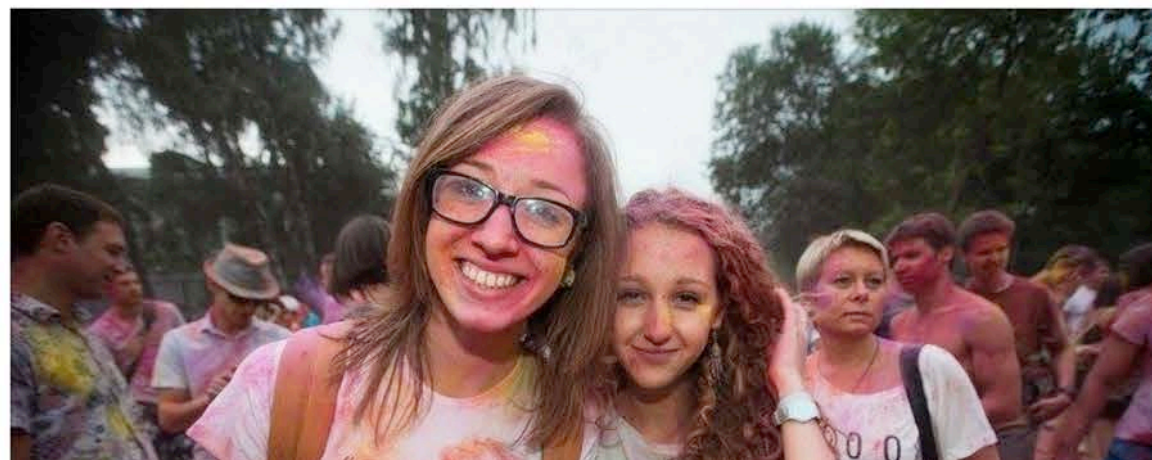
wrong gender for name

PHOTOS



Debera Sabado changed his profile picture.

Yesterday at 21:26



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\$20 Gap Inc. eGiftC... OldNavy.com When you spend \$50+ at OldNavy.com w/ Visa Checkout. Thru 12/16 - Ltd Qty. Terms Apply.



STARTING A SITE? SPOT SPAMMERS

# February 2015

Calendar<sup>co.uk</sup>*pedia*  
Your source for calendars

Wk	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
							1
5							
	2	3	4	5	6	7	8
6							
	9	10	11	12	13	14	15
7							
	16	17	18	19	20	21	22
8							
	23	24	25	26	27	28	
9							

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Data provided 'as is' without warranty

## STARTING A SITE? TRACK KEY INFO



- ✓ Offer info of interest to members
- ✓ Respond to requests
- ✓ “Like” posts
- ✓ Welcome new members
- ✓ Celebrate success
- ✓ Boost confidence



STARTING A SITE? GIVE MORE THAN YOU TAKE

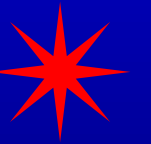


# Facebook Sites to Join



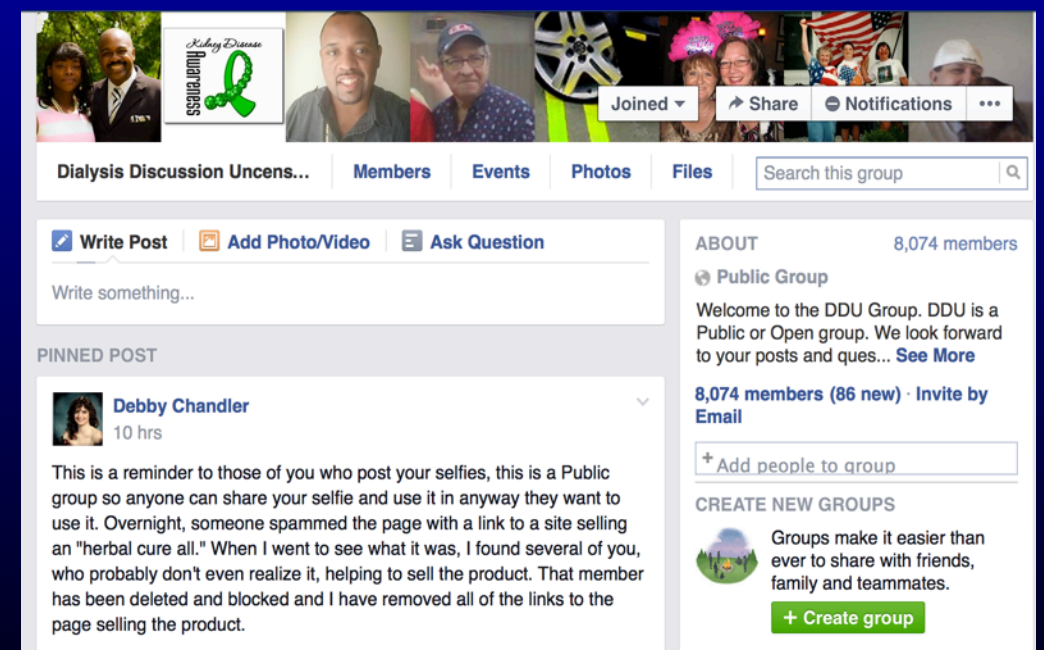
<https://www.facebook.com/groups/HomeDialysisCentral/>

## HDC



<https://www.facebook.com/groups/DialysisUncensored/>

## DDU



# www.mydialysischoice.org

## My life, My Dialysis Choice

a program of the non-profit 

If your kidneys fail, dialysis  
can save your life.

But, dialysis is not just a  
medical treatment.

It can also affect every  
aspect of your lifestyle.

This tool will help you choose the right treatment  
for *you*, so you can feel your best *and* live the way  
you want to.

Get Started 

# Take Aways

- ✦ **People with kidney failure are in chaos**
- ✦ **THEIR priority is their lives—not their Kt/V**
- ✦ **Social media can help you understand consumers**