

Home Dialysis & Beyond: A Patient Experience

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Home Dialyzors United

Njurmedicinskt Vårmöte
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Please excuse me
for my poor English!

It's just a little better
than my unintelligible Swedish!

Itâ 's bara lite bättre
än min obegripliga svenska!

Not Going to Preach to the Choir



- I'll just tell it like it was...and is!
- Well, maybe a little!

My Story on Dialysis

Renal History

- ❖ Adult Hypertension and Obesity
- ❖ 1998 — RCC, Nephrectomy
- ❖ 2003 — Started In-Center Dialysis, 3 x 4
- ❖ 2006 — Began Short Daily @ home, 6 x 2½
- ❖ 2007 — Founded NxStageUsers
- ❖ 2008 — Began Nightly Dialysis @ home, 5x7½

Uh Oh, You're Now CKD4

- ◉ Informed Consent: What are the options?
 - Do nothing and die!

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 - Do nothing and die!
 - Transplant — have a donor or get on “The List”
 - Peritoneal — with my body? No Way!
 - Hemo — looks like the best bet!

OK, Hemo. Now what?

- You can do it in-center!
 - Have professionals to take care of you.
 - Can socialize with others as you get treated.
 - No need for equipment or supplies at home.

OK, Hemo. Now what?

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- Have professionals to take care of you.
- Can socialize with others as you get treated.
- No need for equipment or supplies at home.

- You can do it at home!

- Comfort of own home.
- More flexible schedule.
- Better outcomes.

Decision Time! What to Do?

Seems like a no brainer.
Let's do it at home!

Um well, the program hasn't been approved yet — maybe in two months!

Fast Forward Three Years

Finally on Home Dialysis

You really don't want to know what took so long!

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Finally on Home Dialysis

You really don't want to know what took so long!

Actually, you do want to know!

Flash Back Three Years!

- Meet the Dietician

- What do mean I have to minimize my fluids?

I mean — like — I drink a ton!

Flash Back Three Years!

◉ Meet the Dietician

- What do mean I have to minimize my fluids?

I mean — like — I drink a ton!

- What are these things called phosphorus and potassium?

You mean I've got to cut down on foods that contain them? You've got to be kidding!

Waiting for Home

- ◉ Administrators and Attorneys dilly dally
- ◉ Decisions put off
- ◉ Waiting for home becomes more distant
- ◉ Continue in-center and feeling the effects

In-center Conventional Hemo

- Professionals not exactly professional!
- Socializing — only with a very few!
- Cramps, Nausea, BP Crashes
- Wasted after therapy — slept rest of day
- Brrr! So much snow and bitter cold!

Home Dialysis Again

- ◉ This time dialysis center to start home program
- ◉ I'm the first
- ◉ Should happen soon

Well think again!!!!!!

Continue In-center

- More BP crashes
- Interdialytic weight gain less, but can't handle as much UF as before

Continue In-center

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Have heart attack driving home from therapy
— not my idea of going home

Insurance Changes: New Center

- ◉ Try in-center nocturnal — bad experiment
- ◉ Go back to conventional

3rd Chance the Charm?

- Meet home staff and see machine one week before training
- Last minute decision by VP — scrub it!

More Conventional

- ◉ Can't handle fluid
- ◉ Start going an extra day
- ◉ Getting more and more depressed

Demand Home

- ◉ A break through — newspaper article on other hospital's home program
- ◉ I write and demand home treatment
- ◉ Message Chairman of Board, Hospital President and every VP that mattered.
- ◉ Not going to play nice guy anymore
- ◉ Still took another couple of months and additional efforts.

SDD: A New Beginning

- ◉ Finally, I'm in charge of my life again!
My schedule is my own!

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- ◉ I can travel too!!!!

I've got my life back — Hooray!!!!!!!

NHHD: Even A Better Place

- ◉ More Freedom — have “normal” day
- ◉ Much more energy
- ◉ Fewer meds — no binders, no cinacalcet
- ◉ More optimal outcomes — Kt/V, Phosphorus, Potassium, PTH
- ◉ EF% even increases

Home is where the heart is —
I'm where I should be

Dialysis doesn't have to mean the end of life



But with home dialysis,
it can be a new beginning!

Please Raise Your Hands

If necessary,
would you do
conventional
dialysis 3 times
per week in a
hospital setting?



In the United States

- 90% of nephrologists prescribe conventional hemodialysis therapy which they would not do themselves.

In the United States

- 90% of nephrologists prescribe conventional hemodialysis therapy which they would not do themselves.
- Only 9% of dialysis patients dialyze at home — outside of the center.

Problems with Center Dialysis

Problems with In-center

❖ Fluid Overload



Problems with In-center

❖ Fluid Overload

❖ Anemia



Problems with In-center

- ❖ Fluid Overload
- ❖ Anemia
- ❖ Depression



Problems with In-center

- ❖ Fluid Overload
- ❖ Anemia
- ❖ Depression
- ❖ Dietary Restrictions



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- ❖ Transportation



Problems with In-center

- ❖ Fluid Overload
- ❖ Anemia
- ❖ Depression
- ❖ Dietary Restrictions
- ❖ Too Many Meds
- ❖ Transportation
- ❖ Poor Quality of Life

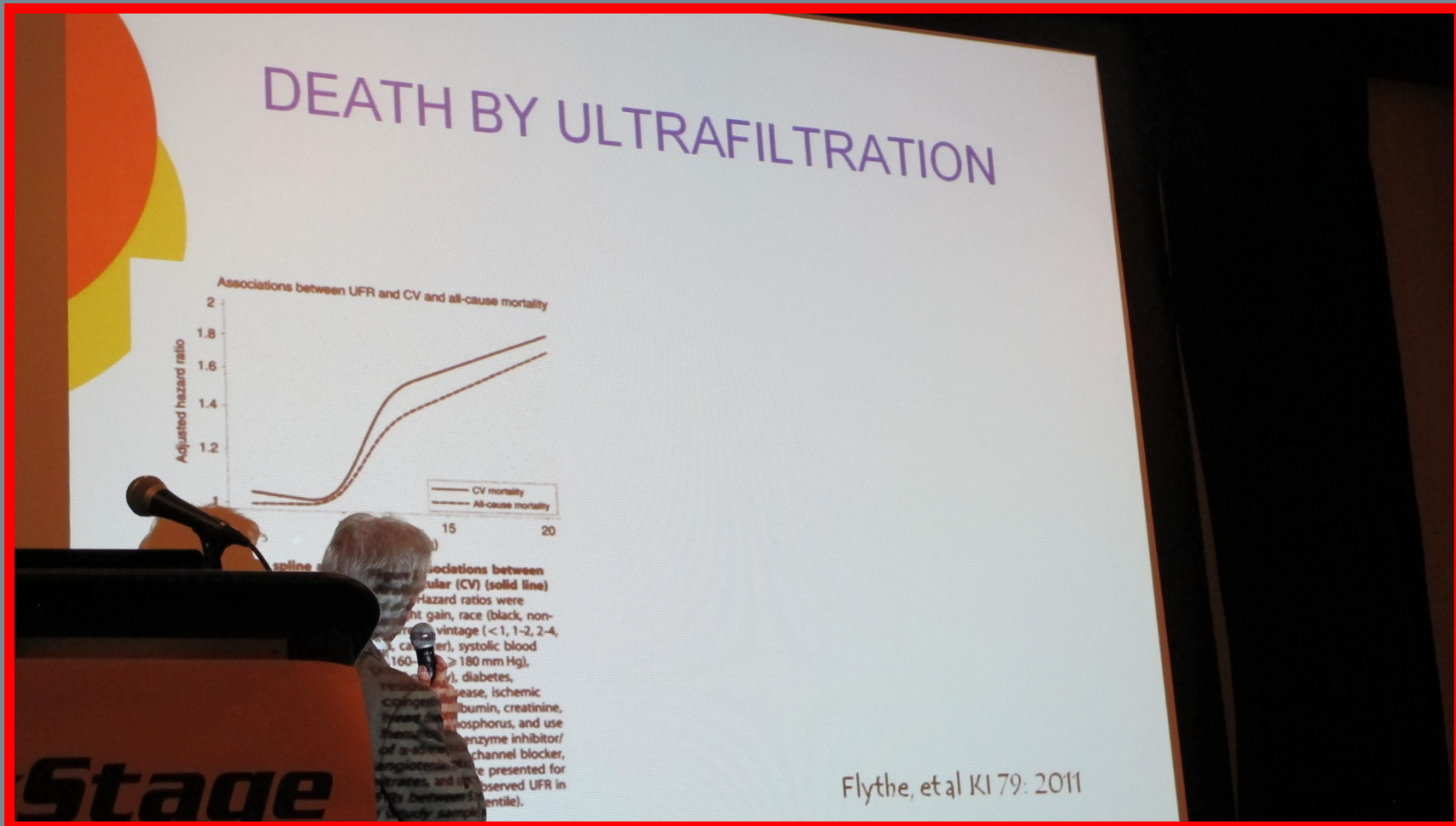


Problems with In-center

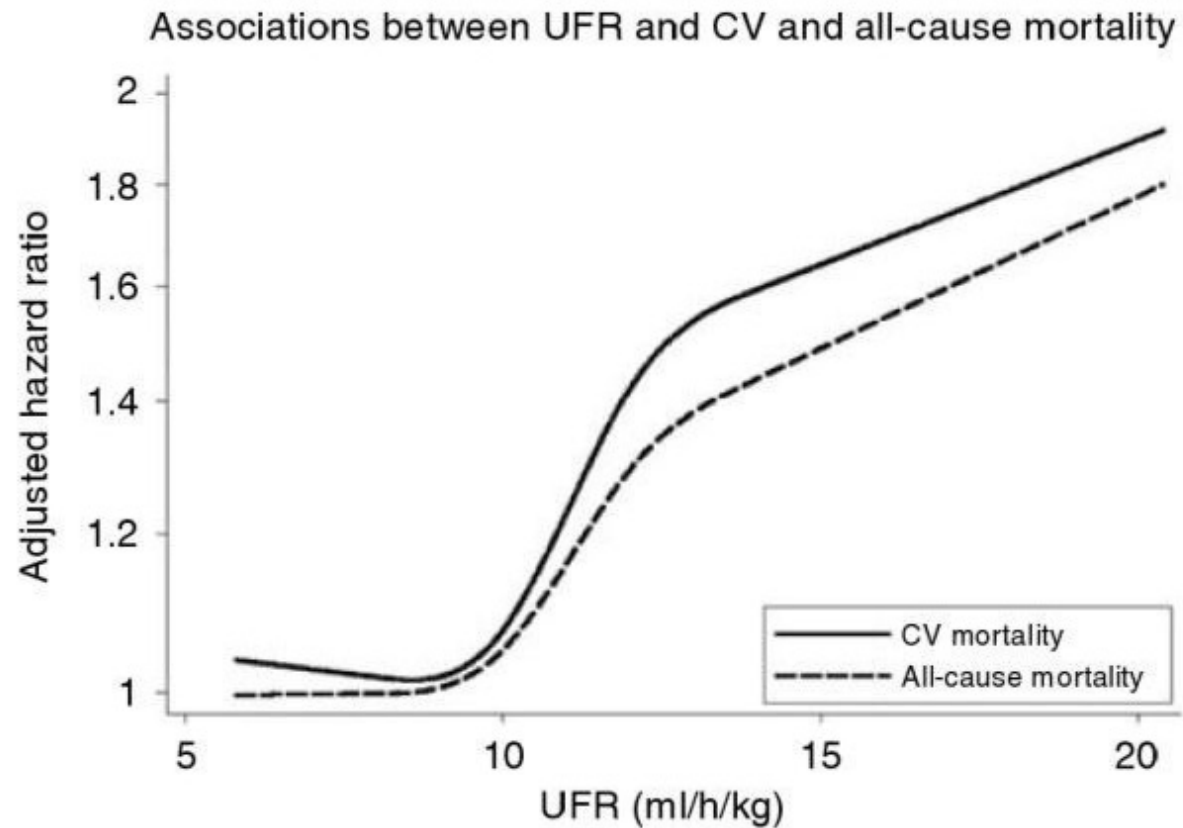
- ❖ Fluid Overload
- ❖ Anemia
- ❖ Depression
- ❖ Dietary Restrictions
- ❖ Too Many Meds
- ❖ Travel
- ❖ Poor Quality of Life
- ❖ The “Long Weekend”



Sucking the Fluid Out



Watch the Fluid Removal



Source: Kidney Int © 2011 International Society of Nephrology

UFR Mortality Risk Factor :

In-center UFR 3xWeek – 4 hr therapy: 1.5kg/day for 75kg person

ONE DAY INTERVAL

- Fluid to remove - 3.0
- Therapy in Hours - 4 hrs.
- Weight in Kg – 75
- Risk Factor – 10.0

LONG WEEKEND

- Fluid to remove - 4.5
- Therapy in Hours - 4 hrs.
- Weight in Kg – 75
- Risk Factor – 15.0

UFR Mortality Risk Factor : HHD– 3 hr therapy: 1.5kg/day for 75kg person

~~NEXT DAY INTERVAL~~

- Fluid to remove - 1.5
- Therapy in Hours - 3 hrs.
- Weight in Kg – 75
- Risk Factor – 6.7

~~TWO DAY INTERVAL~~

- Fluid to remove - 3.0
- Therapy in Hours - 3 hrs.
- Weight in Kg – 75
- Risk Factor – 13.3

UFR Mortality Risk Factor :

HHD– 7½ hr therapy:
1.5kg/day for 75kg person

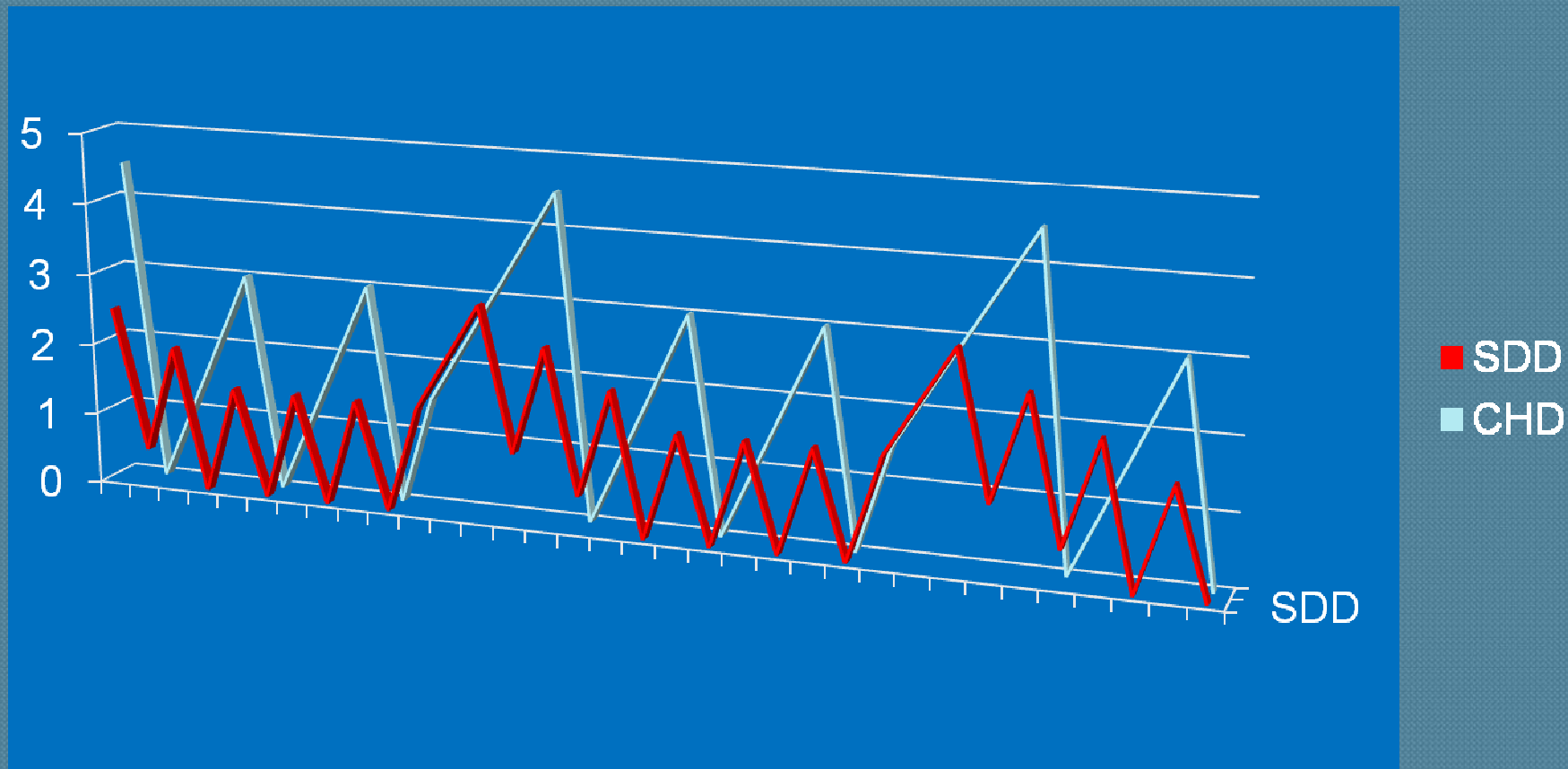
~~NEXT DAY INTERVAL~~

- Fluid to remove - 1.5
- Therapy in Hours - 7½ hrs.
- Weight in Kg – 75
- Risk Factor – 2.7

~~TWO DAY INTERVAL~~

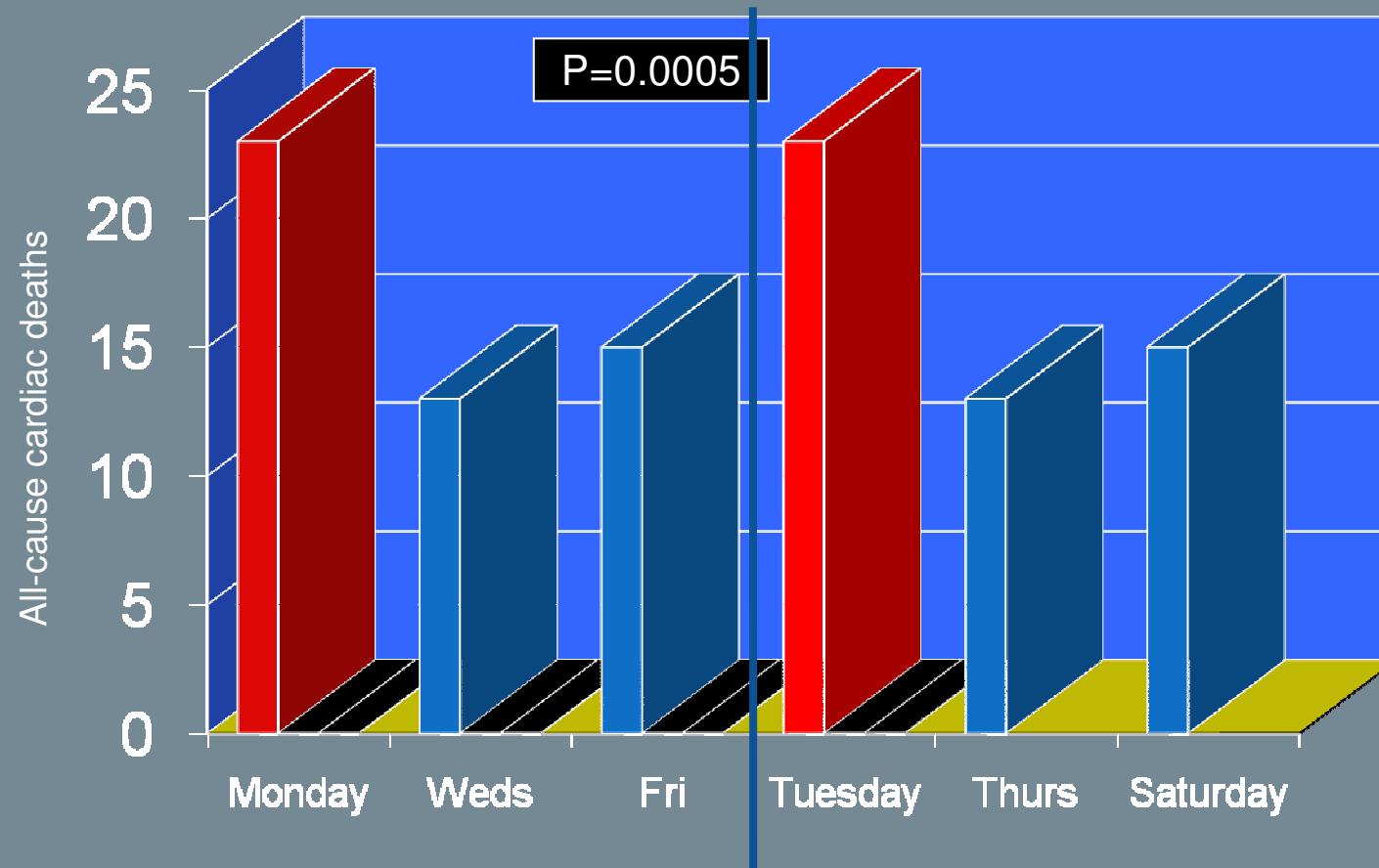
- Fluid to remove - 3.0
- Therapy in Hours - 7½ hrs.
- Weight in Kg – 75
- Risk Factor – 5.3

Why one feels better with 6xWeek SDD vs. 3xWeek CHD



Toxins removed more often
Less interdialytic fluid gain
Assumes 1.5L gain per day; max 2.0L SDD UF and CHD UF to DW

Standard Hemodialysis: Killer Weekend



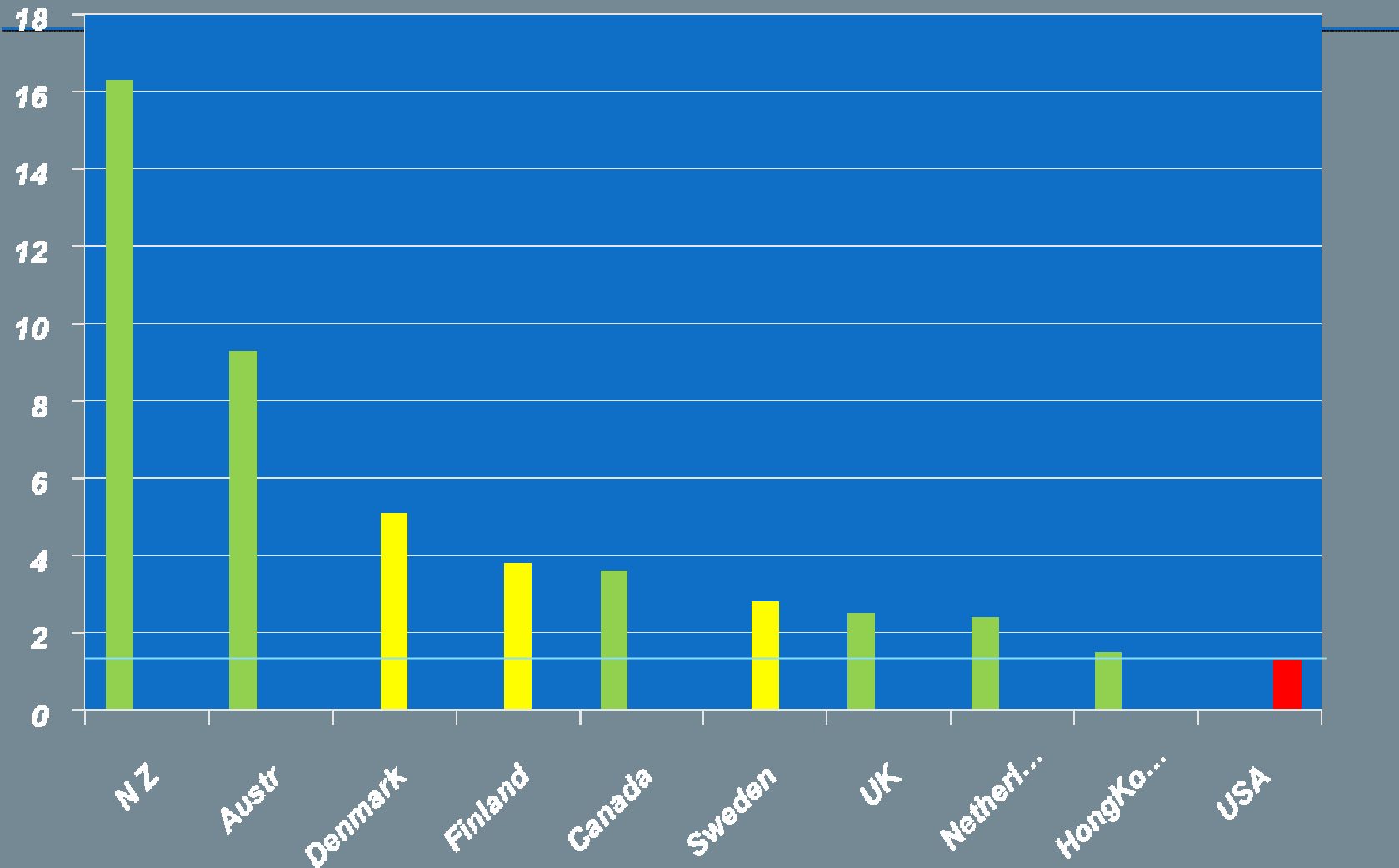
Bleyer AJ, Russell GB, Satko SG. Sudden and cardiac death rates in hemodialysis patients. *Kidney Int.* 1999 55:1553

General Conclusions: In-Center

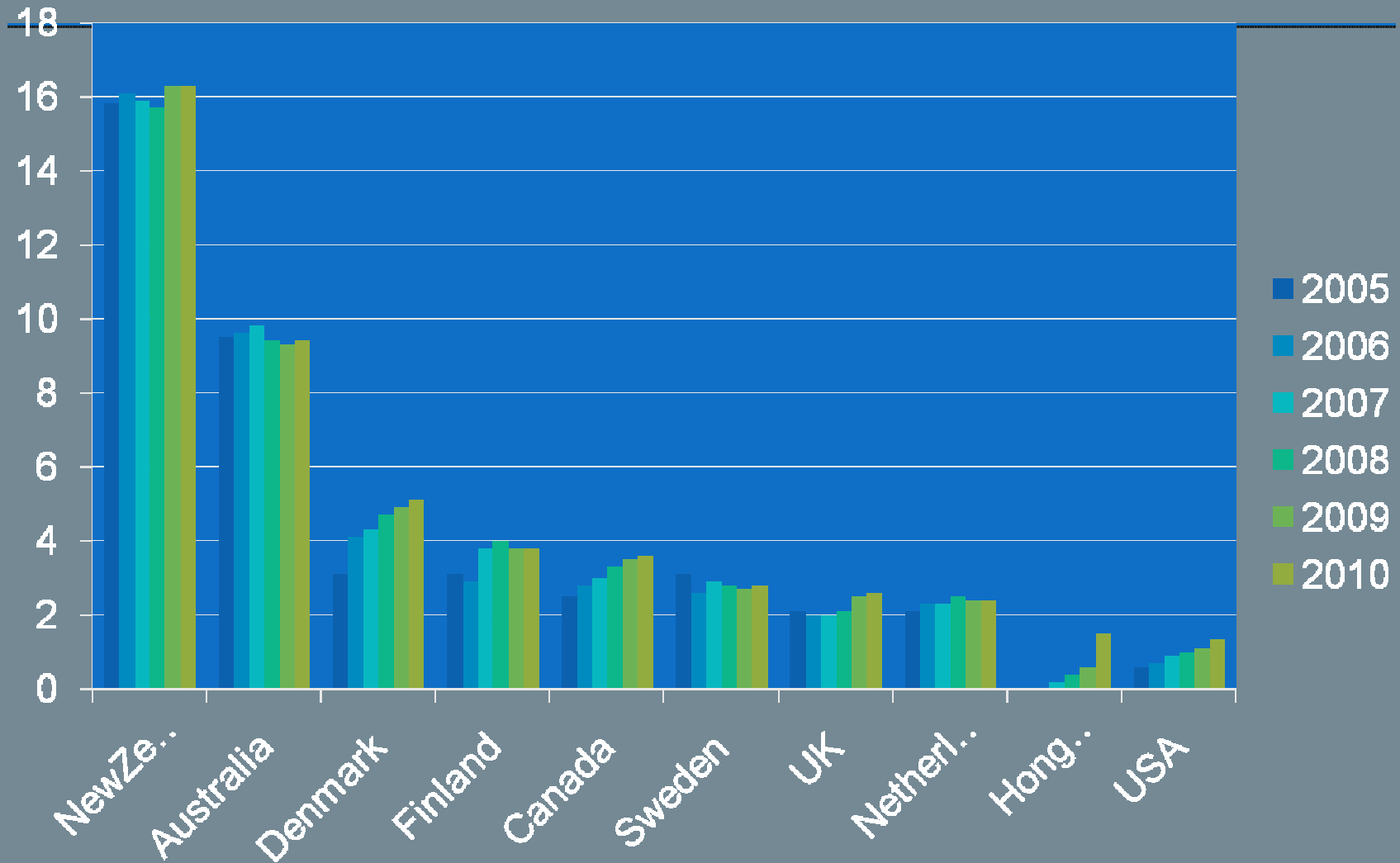
- ◉ Does not provide rehabilitative dialysis
- ◉ Does not maintain wellness
- ◉ Patient loses control of life
- ◉ Does not treat patient holistically
- ◉ Mortality rate too high
- ◉ Long term complications

World View of Home Dialysis

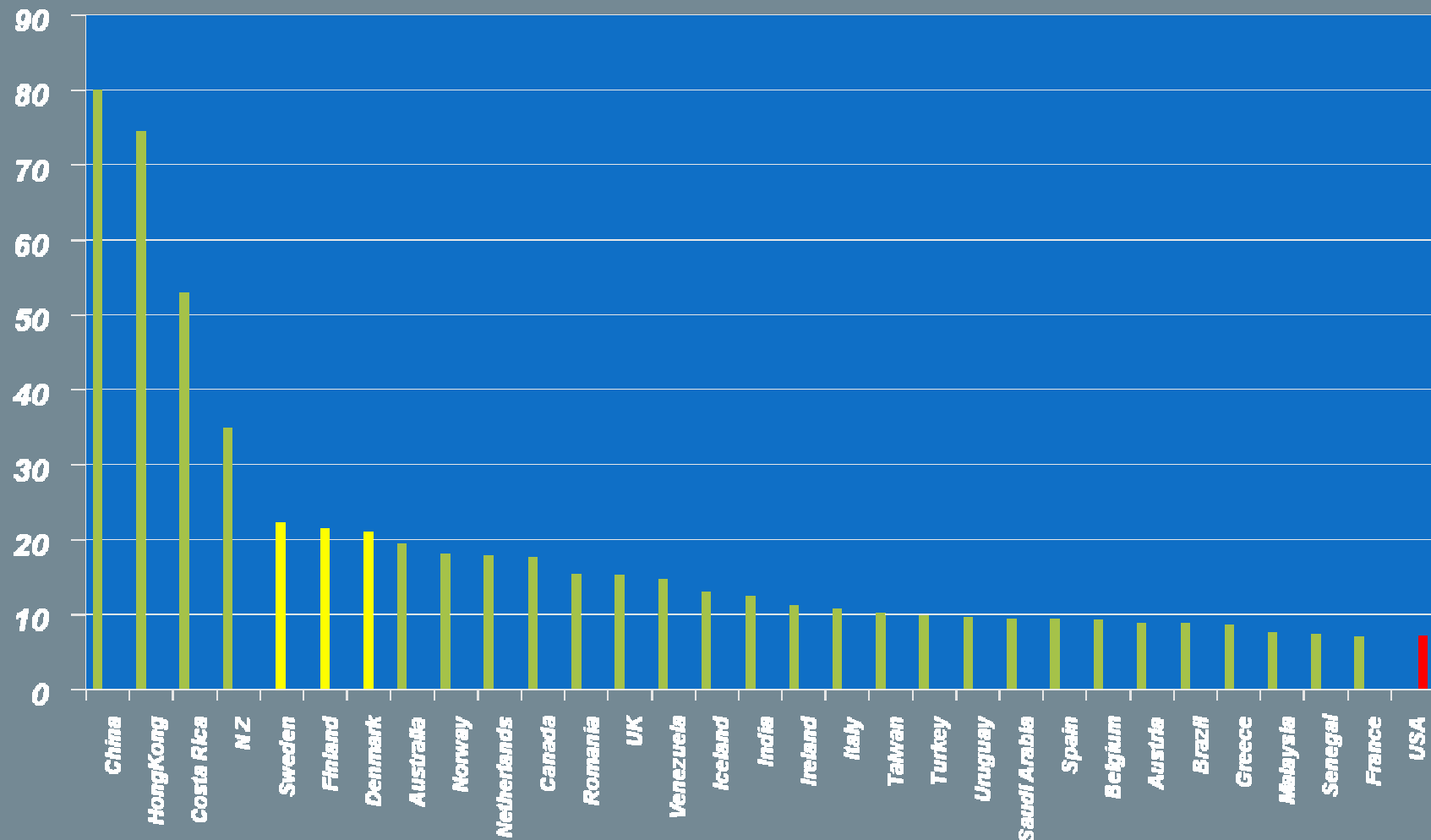
Percentage Home Hemodialysis Patients by Country



Percentage Home Hemodialysis by Country, 2005-2010



Percentage Peritoneal Patients by Country



CKF Prevalence

	Sweden	Denmark	Finland	Norway	Iceland	U.S.
	2010	2010	2009	2010	2009	2009
Total CKF patients	8,501	4,708	4,167	4,193	172	571,414
Transplanted Patients	4,740	2,132	2,427	2,975	102	172,553
Transplants per Year	418	232	176	263	7	17,336
Hemo in-center or hospital	2,823	1,879	1,327	990	61	366,791
PD	841	565	378	220	9	27,559
HHD	97	132	67	8	1	4,511

Dialysis Prevalence

	Sweden	Denmark	Finland	Norway	Iceland	U.S.
	2010	2010	2009	2010	2009	2009
Total CKF patients	8,501	4,708	4,167	4,193	172	571,414
Total Dialysis	3,761	2,576	1,772	1,218	71	298,858
Hemo in-center or hospital	2,823	1,879	1,327	990	61	366,791
% In-center	75.1%	72.9%	74.9%	81.3%	85.9%	92.0%
PD	841	565	378	220	9	27,559
% PD	22.4%	21.9%	21.3%	18.1%	12.7%	6.9%
HHD	97	132	67	8	1	4,511
% HHD	2.6%	5.1%	3.8%	0.7%	1.4%	1.1%

U.S. Lagging Behind World

Why am I lecturing here?

You should be lecturing us

U.S. Lagging Behind World

Why am I lecturing here?

You should be lecturing us

But we are using portable hemodialysis machines

Bit of U.S. History

Social Security Act §1881

Original Intent Clear About Home Dialysis & Rehabilitation

It is the intent of the Congress that the maximum practical number of patients who are medically, socially, and psychologically suitable candidates for home dialysis or transplantation should be so treated and that the maximum practical number of patients who are suitable candidates for vocational rehabilitation services be given access to such services and encouraged to return to gainful employment. The Secretary shall consult with appropriate professional and network organizations and consider available evidence relating to developments in research, treatment methods, and technology for home dialysis and transplantation.

Home Dialysis to be Emphasized

On February 3, 1977 Representative Dan Rostenkowski, chairman of the Health Subcommittee of the Committee on Ways and Means, with Representative Vanik, introduced H. R. 3112. **The new bill extended the provision of the earlier one that 50% of renal patients be on home dialysis or in self-dialysis training.**

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On February 3, 1977 Representative Dan Rostenkowski, chairman of the Health Subcommittee of the Committee on Ways and Means, with Representative Vanik, introduced H. R. 10111. The new bill extended the provision of the earlier one that 50% of renal patients be on home dialysis or in self-dialysis training.

Rehabilitation: The Name of the Game

Belding Scribner said



“If the treatment of chronic uremia cannot fully rehabilitate the patient, the treatment is inadequate.”

Objective of Renal Rehabilitation?

“Chronic patients must be offered support to enable them to make the best of their remaining good health and live as full a life as possible”.

Guidelines for the Care of Kidney Patients
Riksförbundet för Njursjuka

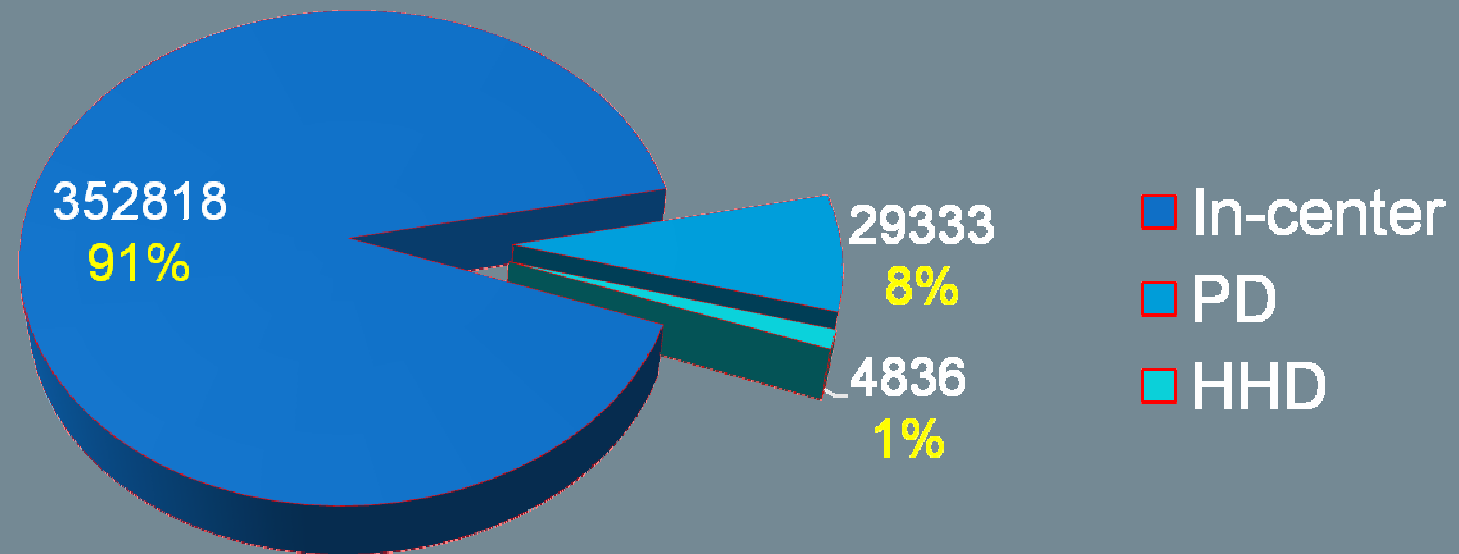
U.S. State of Rehabilitation

❖ Dialysis Patients 18-54 y.o.	121,667	
❖ Employed	25,124	21%
❖ Employed FT/PT through Rehab	2,973	2%
❖ Attending school	3,965	3%
❖ Dialysis facilities	5,591	
❖ Facilities w/dialysis after 5pm	1,332	24%

Source: 2009 Consolidated Network Report, Table 20

Number of Dialysis Patients

By Modality - 2009

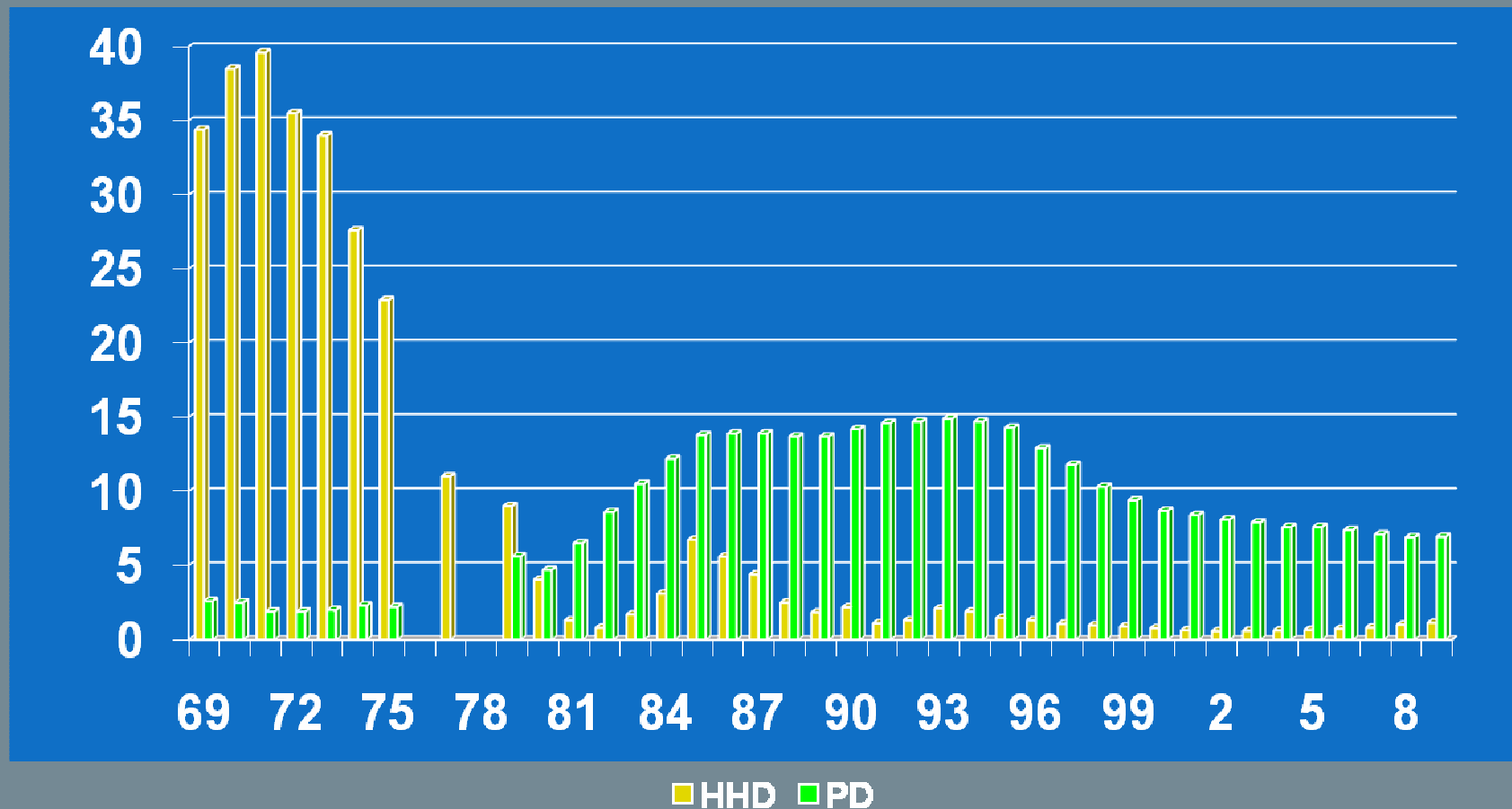


Source: 2009 Consolidated Network Report, Tables 12 & 13

Worth Mentioning Again — Go Figure!

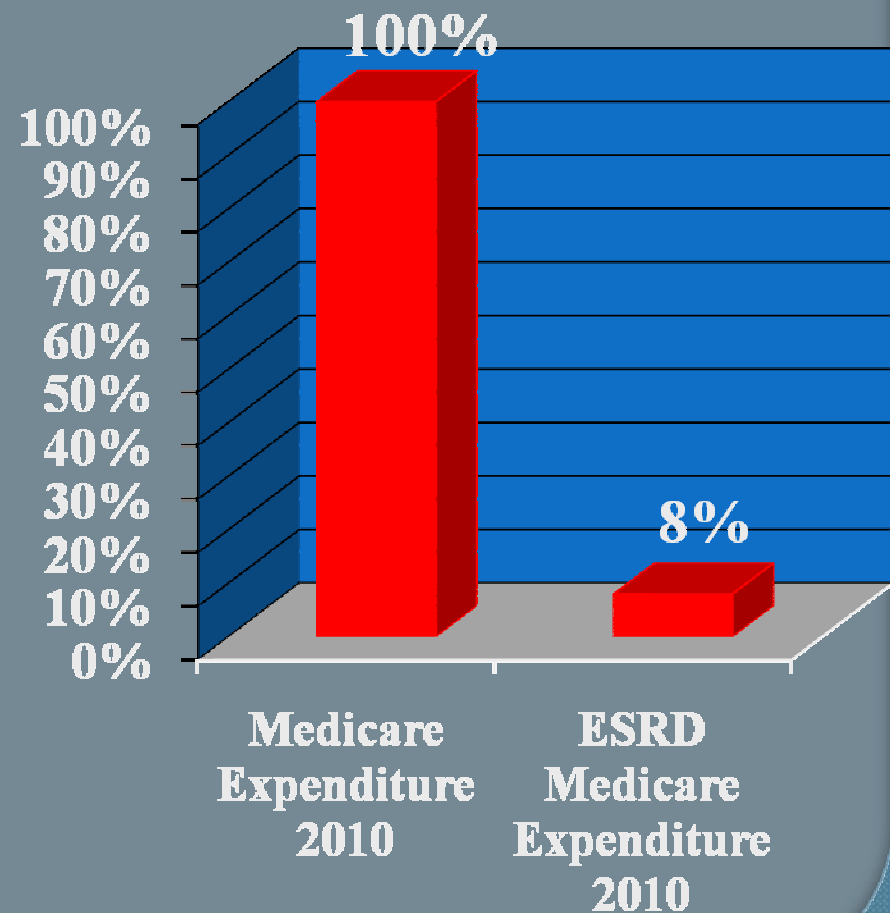
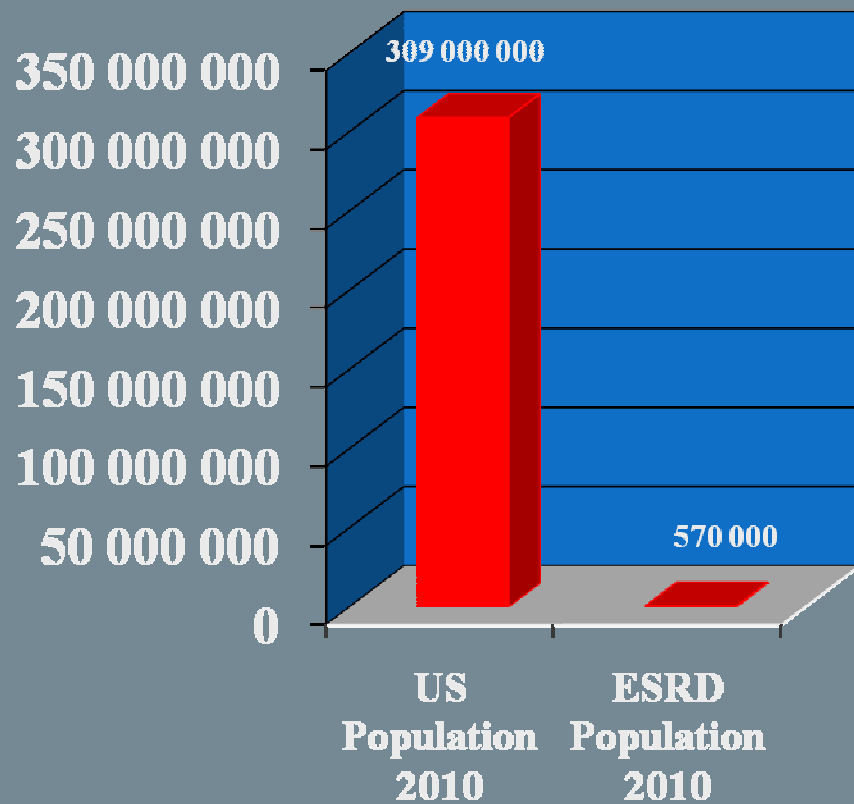
- Approximately 90% of Nephrologists would choose home dialysis for themselves.
- Yet 91% of their patients are prescribed the therapy they wouldn't do themselves.

Percent U.S. dialysis patients on home hemodialysis and peritoneal, 1969 to 2009

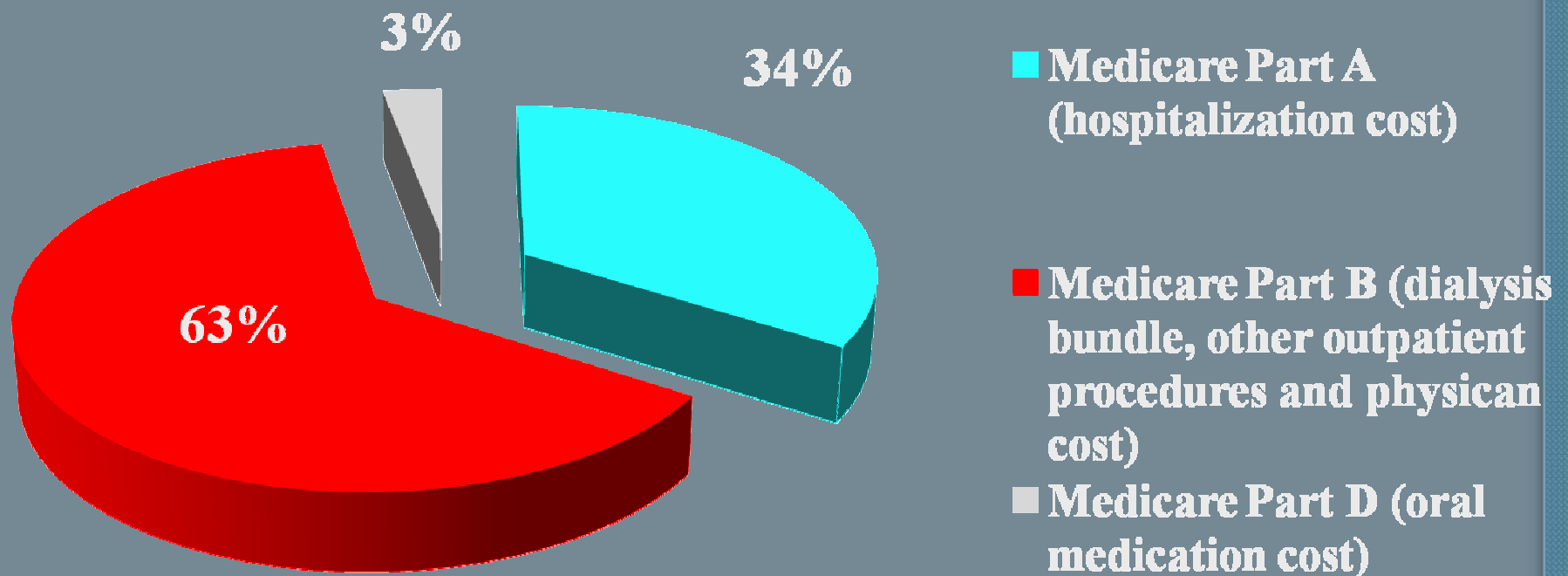


US population Vs CKF population

CKF % of Medicare expenditure 2010



Average estimated dialysis patient cost per year \$82,000



U.S. Cost of Disability

U.S. Dollars

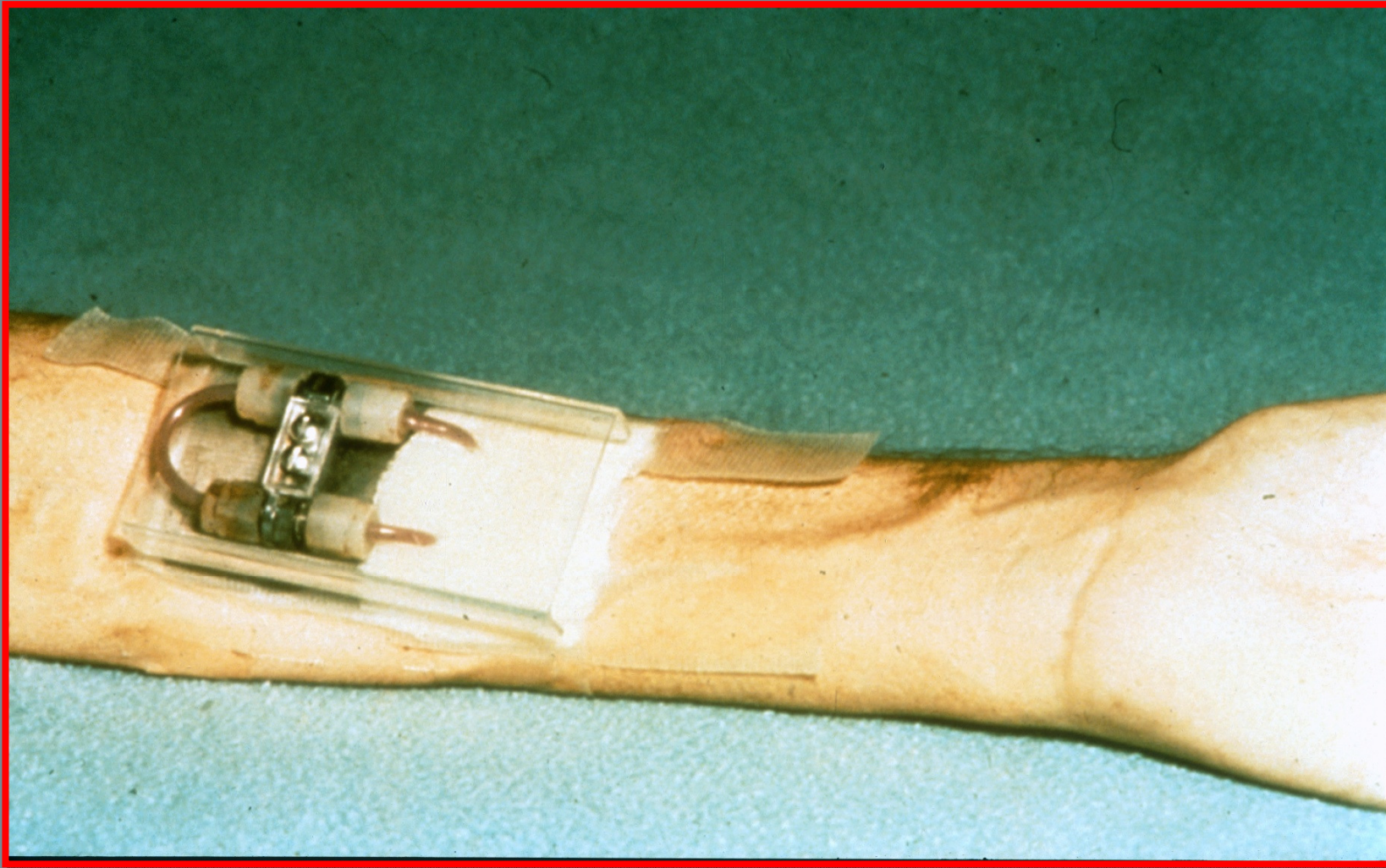
- 96,000 patients between ages of 18-54 unemployed
- Avg disability payment per month is \$1100
- Yearly cost is \$1,267,200,000

Swedish Krona

- 96.000 patienter mellan åldrarna 18-54 arbetslösa
- Genomsnittligt funktionshinder betalning per månad är 7544 SEK
- Årliga kostnaden är 8,690,688,000 SEK

How Did We Get Here

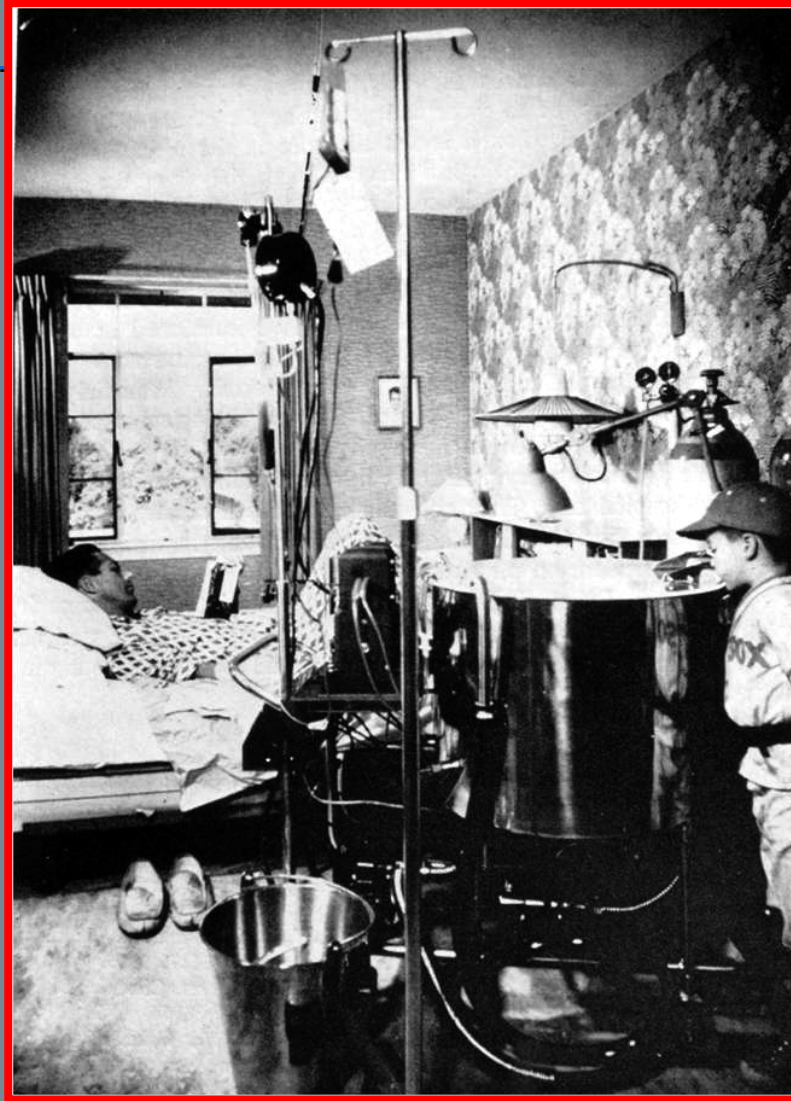
Scribner shunt, March 1960



Seattle Original 3-bed Unit, 1962



Boston, 1964



Home hemodialysis Training, Seattle, June 1964



The First Nocturnal Overnight Unattended Home Hemodialysis, London, October 1964



We've Come a Long Way



Nils Alwall & Holger Crafoord with 1st Gambro Dialysis Machine

We've Come a Long Way



NxStage System One

And We Need to Go Further

Challenges for the Future

Challenges for the Future

- ◉ Smaller, Lighter & Easier Machines
- ◉ More Efficient & Healthier Machines
- ◉ Longer, Slower and Accessible
- ◉ More Holistic Therapy
- ◉ Rehabilitation, Rehabilitation and More
- ◉ Better Quality of Life for All

Challenges for Right Now

- ◉ Stop using barriers to home dialysis as an excuse. Thousands have overcome
- ◉ Do more complete informed consents
- ◉ Give your patients the benefit of doubt
- ◉ Promote peer-to-peer support
- ◉ Get up to date with current literature
- ◉ Listen and learn from your patients & care partners
- ◉ Get your colleagues on board

More HHD Machines Coming

- ◉ Fresenius Baby K@Home Sorbent
- ◉ Quanta SelfCare+
- ◉ Baxter HomeChoice Hemo
- ◉ Fresenius PAK
- ◉ NxStage System Two

- ◉ WAK
- ◉ Implantable

Playing it Safe



Sweden's own

Redsense

Blood Leak
Detector

Awarded 2012 Patient
Safety Improvement
Award —

Renal Physician
Association

Redefining Terms for a New Day

ESRD vs. CKF

- ◉ We don't need negative feelings
- ◉ Many don't get beyond depression
- ◉ People need hope to move forward

- ◉ We're not at the end of anything
- ◉ We can "cure" our kidney failure with optimal dialysis
- ◉ We haven't failed; just our kidneys have

End Stage Renal Disease: A Negative Spin That Serves No Good Purpose

Just the thought of it can
put a person in a
downward spiral toward
an early grave.

Keep yourself and
the message positive.



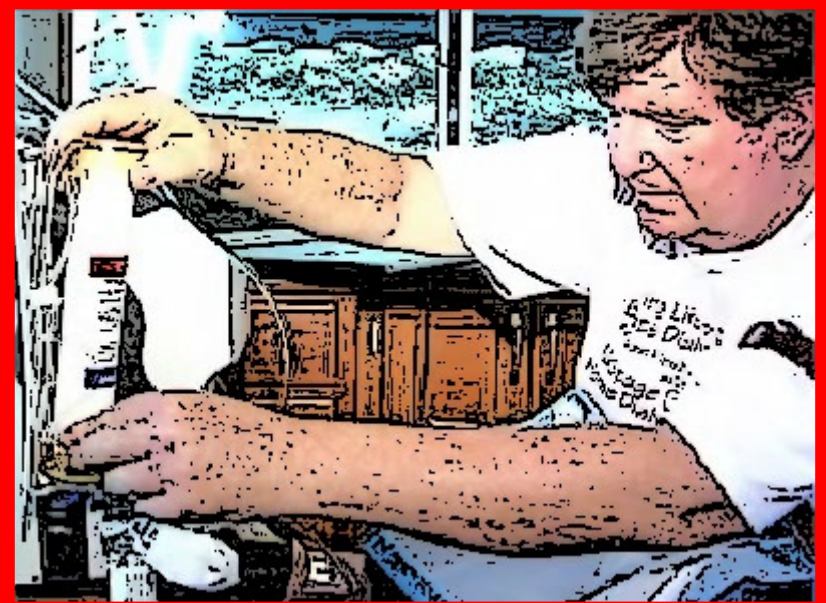
Adequate vs. Optimal

- What is adequate?
- Is it just enough?
- Enough for what? Survival?
- What is optimal?
- Getting better treatment.
- Living a more quality life with fewer side effects.
- Quality indicators are different

Which are you?



Dialysis Patient



Dialyzer

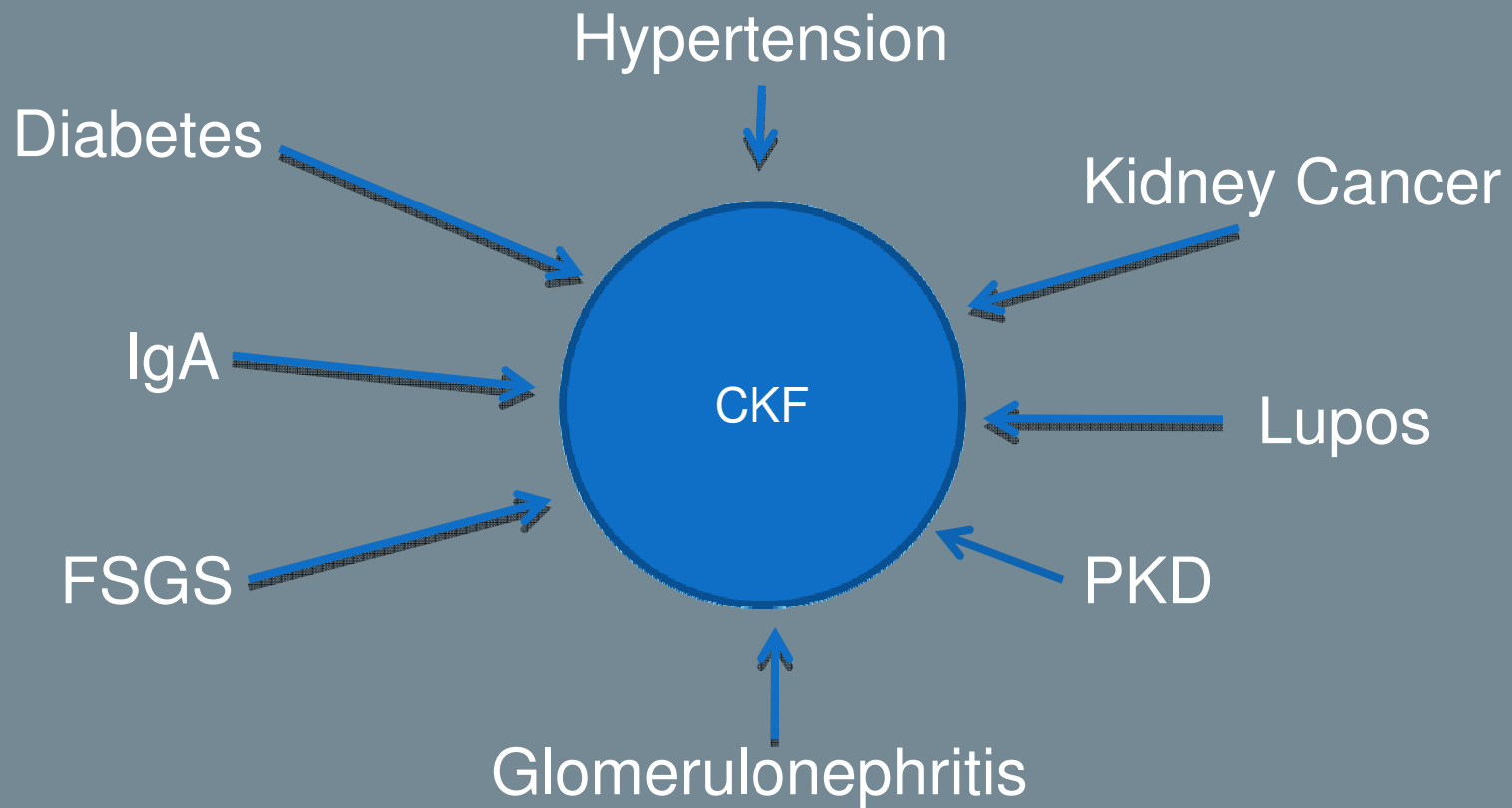
Passive vs. Active



Care Partner vs. Caregiver

- Care giver takes charge and manages patient's treatment and affairs, being practically a nurse and more.
- Care partner shares the responsibilities and management for the dialyzer's treatment and one who work together effectively and respectfully for the long run.

Is Kidney Failure a Disease?



If Not a Disease? Treatment?

- ◉ Is dialysis (and transplant) a treatment?
- ◉ Or is it a replacement therapy?

Debilitation vs. Rehabilitation

- Sickness
- Withdrawal
- Low self esteem
- Disability
- Lose will to live

- Wellness
- Participation
- Empowered
- Employment
- Active quality life

Redefine Outcomes

- Patients aren't concerned about lab results
- Rather care about how they feel and ability to live "normal" life
- Focus on wellness — not sickness

Freedom Study on HHD

Study Design & Protocol

- Multi-center, prospective matched cohort study. Patients serve as own control.
- Enrolling up to 500 patients from up to 70 clinical centers. Minimum of 1 year follow-up.
- Eligible patients are adult ESRD patients who require dialysis and have Medicare as their primary payer.
- Study sponsored by NxStage Medical, Inc.

FREEDOM –12 Month Interim Results

Interim Measure	Baseline	Month 12	P - Value
Beck Depression Inventory Score ¹	11.2	7.8	P < 0.001
Post Dialysis Recovery Time (min) ¹	476	63	P < 0.001
% of Patients Reporting Symptoms of Restless Legs Syndrome ²	36%	26%	P = 0.0495
# of Prescribed Anti-Hypertensive Medications ³	1.7	1.0	P < 0.0001
% of Patients NOT Prescribed Anti-Hypertensive Medication ³	21%	47%	P < 0.002
MOS Sleep Scale - Sleep Problems Index I ²	39	33	P = 0.001
MOS Sleep Scale - Sleep Problems Index II ²	41	34	P < 0.001
SF36 - Physical component scale (PCS) ⁴	34	38	P < 0.0001
SF36 - Mental component scale (MCS) ⁴	50	52	P = 0.01

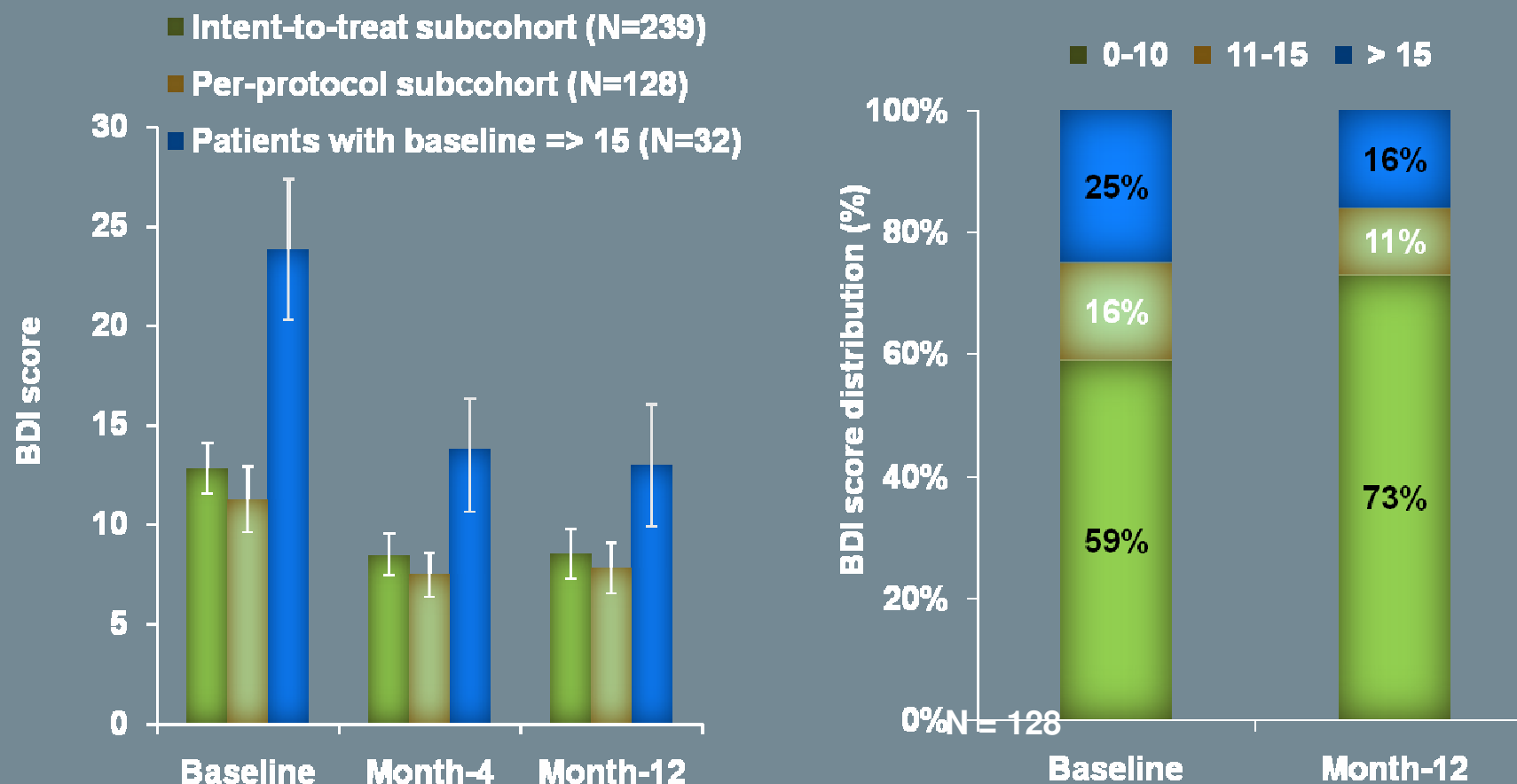
¹Jaber B, et al. Improvements in Depressive Symptoms and Post-Dialysis Recovery Time. Am J Kidney Dis 56:531-539, 2010.

²Jaber B, et al. Improvements in Restless Legs Symptoms and Sleep Disturbances. Clin J Am Soc Nephrol 6: 1049–1056, 2011.

³Jaber B, et al. Poster presentation. SDHD Reduces The Need for Anti-Hypertensive Medications ASN Renal Week 2009.

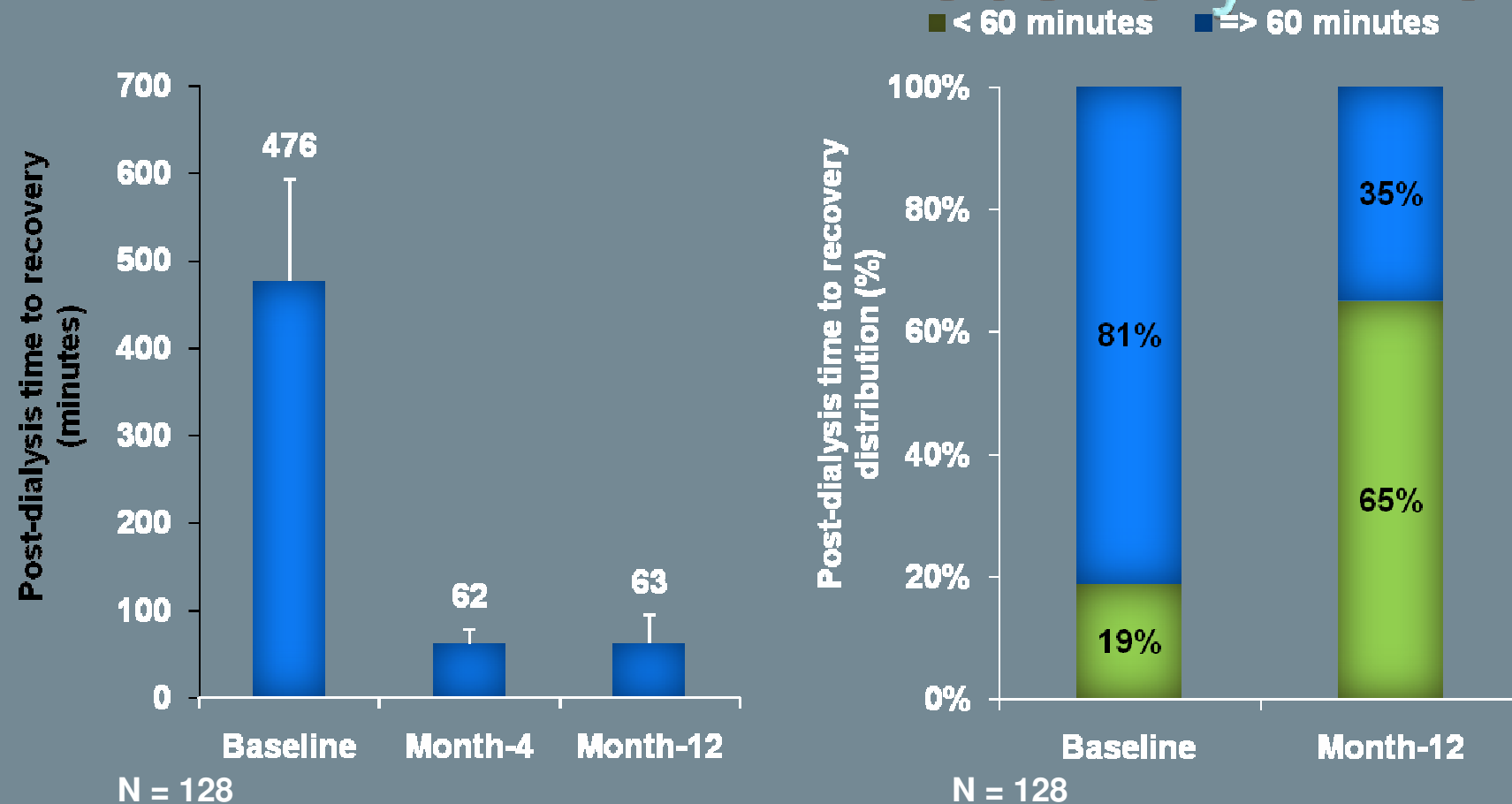
⁴Finkelstein F, et al. SDHD Improves SF-36 Health Survey Domains. Poster presentation ADC 2011

SDHD Reduces Depressive Symptoms (BDI Score)



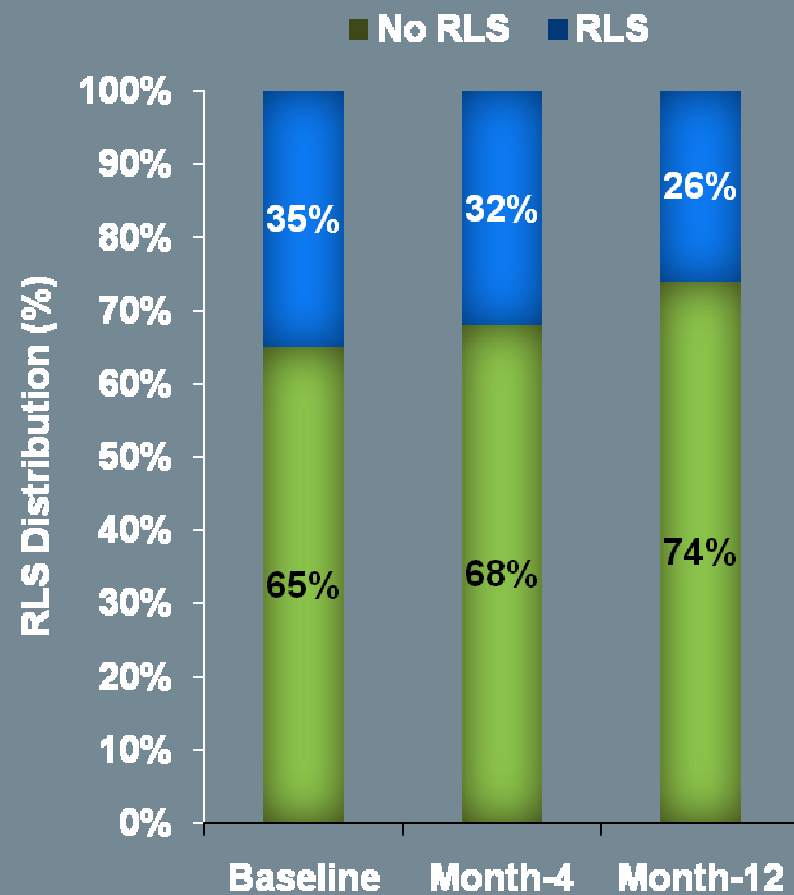
Jaber B, et al. Improvements in Depressive Symptoms and Post-Dialysis Recovery Time. Am J Kidney Dis 56:531-539, 2010.

SDHD Reduces “Post-Dialysis Recovery Time”

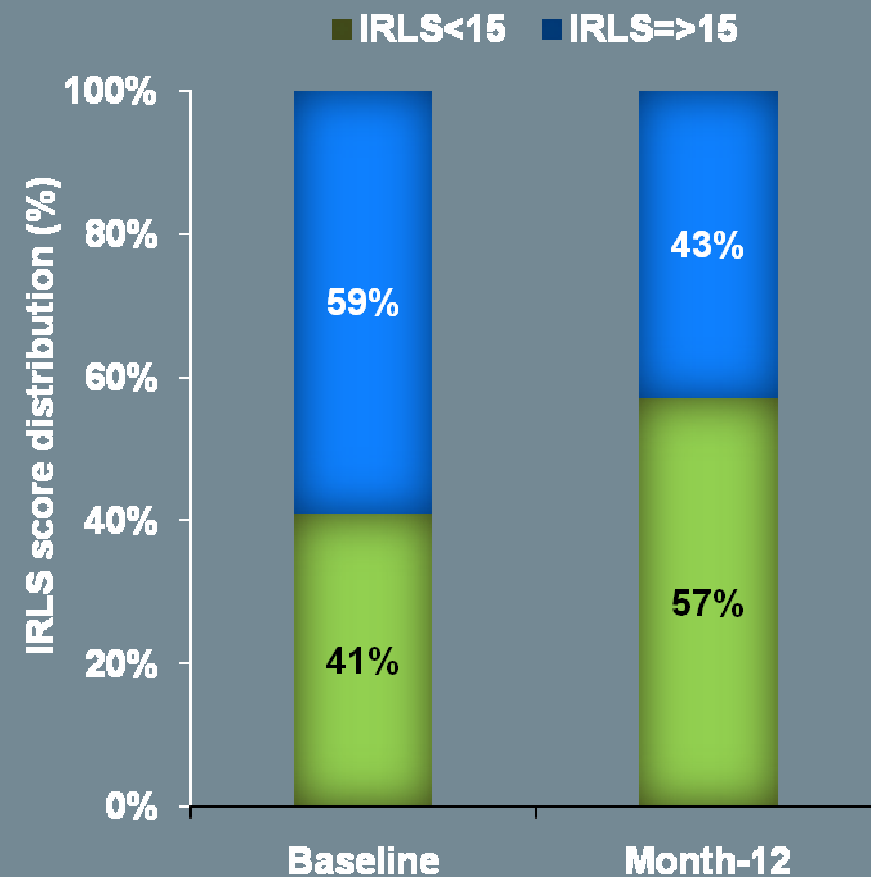


Jaber B, et al. Improvements in Depressive Symptoms and Post-Dialysis Recovery Time. Am J Kidney Dis 56:531-539, 2010.

SDHD Improves Restless Legs Syndrome (IRLSSG scales)

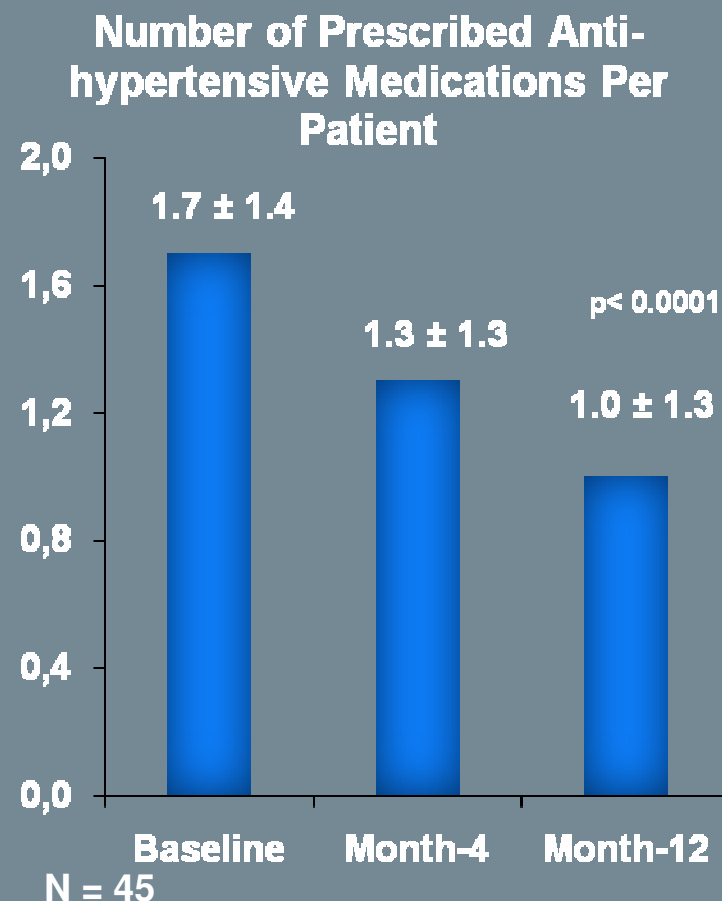
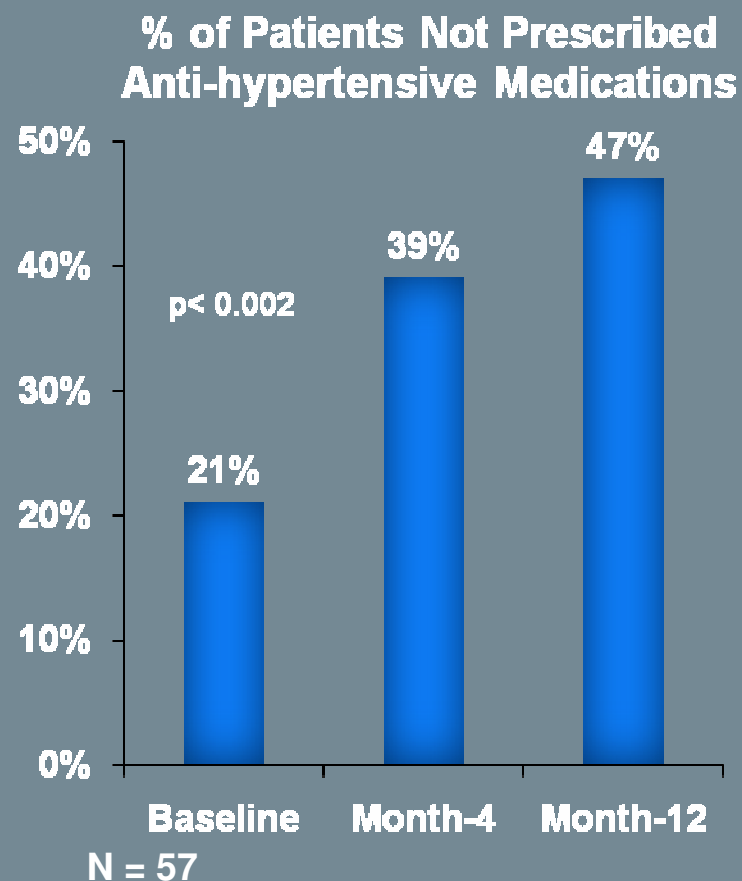


N = 127



N = 46

SDHD Reduces the Need for Anti-Hypertensive Medications

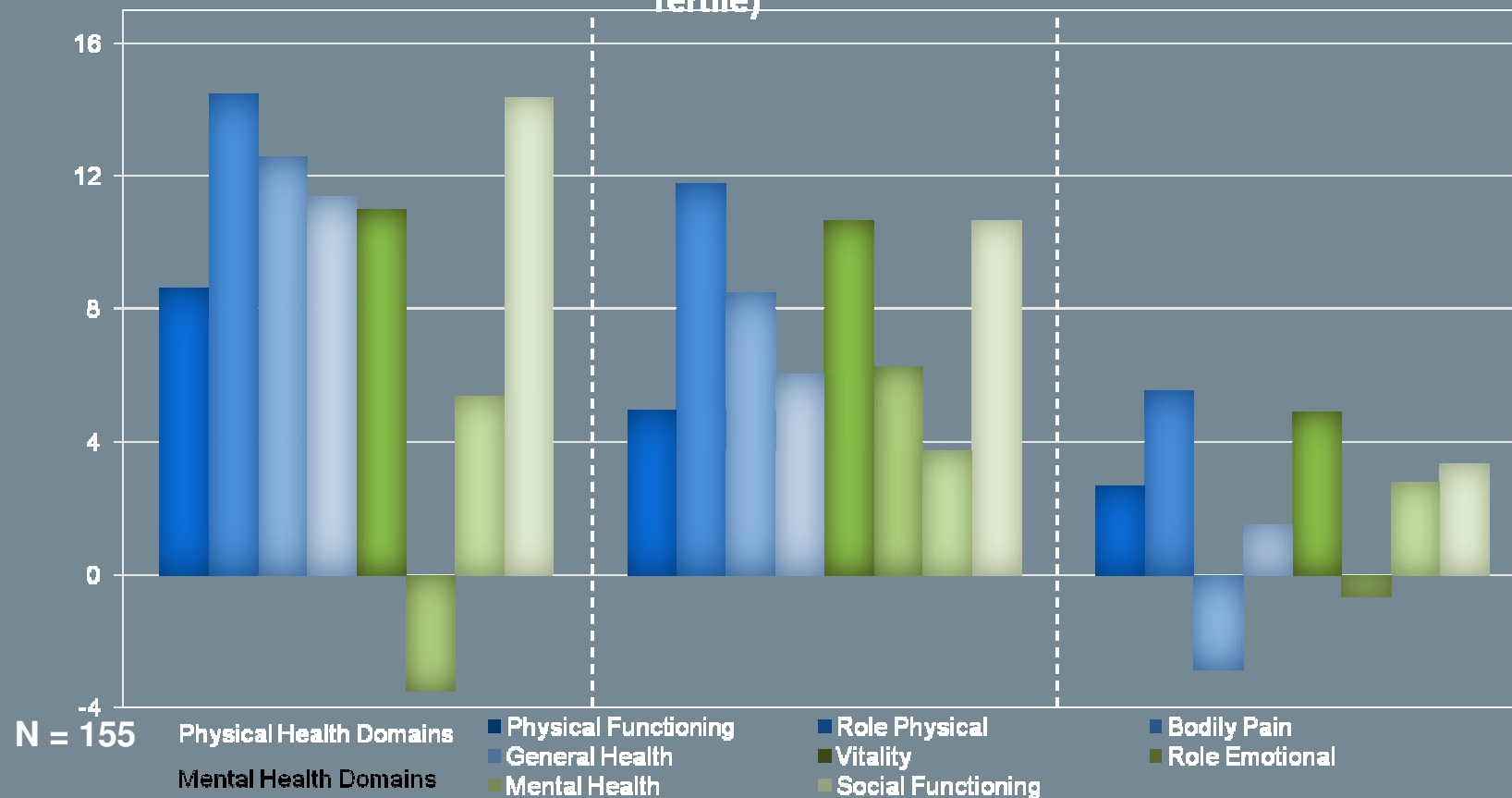


SDHD Improves Sleep Quality (MOS Sleep Survey Scores)

MOS Sleep Scale (N = 127)	Baseline	Month-4	Month-12	P value
Sleep Problems Index I	39 (35, 43)	33 (29, 37)	33 (29, 36)	0.001
Sleep Problems Index II	41 (37, 45)	35 (31, 39)	34 (31, 38)	<0.001
Adequacy of Sleep	49 (44, 54)	52 (47, 57)	53 (49, 58)	0.23
Sleep Disturbances	43 (38, 48)	38 (33, 43)	36 (30, 41)	0.004
Snoring	44 (37, 51)	39 (32, 46)	37 (30, 44)	0.08
Awaken Short of Breath or with a Headache	17 (12, 21)	9 (5, 13)	12 (8, 16)	0.002
Daytime Somnolence	39 (35, 43)	30 (26, 34)	32 (27, 36)	0.0001
Sleep Quantity (hours)	6.5 (6.2, 6.9)	6.6 (6.3, 6.9)	6.6 (6.2, 7.0)	0.9
Optimal Sleep	42 (34, 52)	37 (29, 47)	38 (29, 48)	0.7

SDHD Improves Mental & Physical Health (SF-36 Scores)

Figure 1: 12-Month Change in SF-36 Domain Score (PCS Baseline Tertile)



A Couple of Wise Men

Robert Lockridge, MD, UVA

- “This is probably the most important thing you need to understand: **Age and comorbidity do not exclude people from home hemodialysis.** The people who are retired, in their 70s, with an ejection fraction of 20 percent have a much better chance of doing more frequent short or nocturnal dialysis to prolong their life and improve their quality of life. **If you only pick the college graduate that's 35 years of age, you're not going to treat the people who really need this modality, so don't restrict people.**”

Chris Blagg, MD

- Is it difficult to learn to do your own dialysis? Not particularly. Do not be overwhelmed by the complicated looking machine. If you can drive a car safely, you can certainly learn to operate a dialysis machine equally well. In neither case do you need to know the details of what is under the hood or in the machine. Rather, you have to learn how to use the device safely. Remember, most ordinary people can learn to drive with appropriate training and the same applies to dialysis.

Life Can Be Good
Life Should Be Good



10 dialyzors, care partners and friends
Freedom Cruise, January 2010



Celebrating my birthday
Freedom Cruise, January 2010



Renewing wedding vows
Freedom Cruise, January 2010



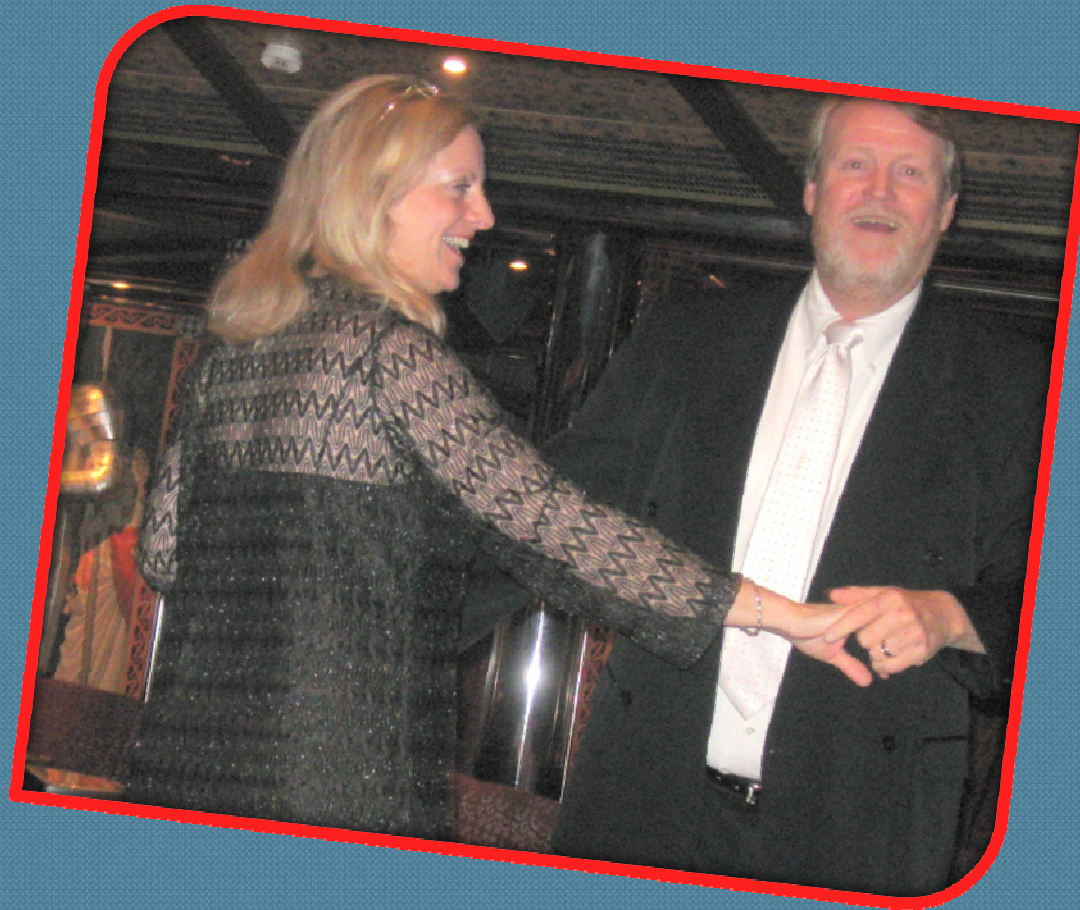
Zippering through the jungle
Freedom Cruise, January 2010



Visiting the ancient ruins
Freedom Cruise, January 2010



First dive
Freedom Cruise, January 2010



Dancing the night away
Freedom Cruise, January 2010



Lounging on the beach
Freedom Cruise, January 2010



Lazing on the river
Freedom Cruise, January 2010



Climbing new heights
Freedom Cruise, January 2010



Jumping for joy



Flyfishing in the wilderness



Shooting the rapids



Backwoods hunting



Horsing around



Clowning around and sharing CKF



Digging life



On an Alaskan ferry



Climbing to New Heights – Mt. Whitney



Rappelling for the fun of it

Belding Scribner said



“What started out in 1960 as a noble experiment gradually has degenerated into a highly controversial billion dollar program riddled with cost overruns and enormous profiteering.”

Testimony at the Senate Finance Health Subcommittee in 1977

Belding Scribner said



“The annual cost of dialysis will drop. Innovations and automation will make the task of self-dialysis simpler to comprehend and less work for the patient. The resulting healthy, well-nourished, normotensive hemodialysis patients will incur lesser additional health care costs than their sickly, malnourished, hypertensive counterparts on short three times weekly hemodialysis!”

Message sent to the Annual Dialysis Conference in 2003

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Dialysis Support and Advocacy

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Greensboro coach isn't letting kidney disease get the best of him

Ricky Lewis was dead for seven minutes before he came back to life. It was Feb. 17, 2005. The sheet had been pulled over his head, his mother had been contacted and directed to make funeral arrangements. His life had ended, at the age of 33. But then, his heart started beating again. To continue [...]

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ANNOUNCEMENTS:

- Check out our Events section which includes our New Orleans Conference

- Our Buddy System is open for business.

Information

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Write something...



Ann Contreras I have MANY more RSVPs to the Meet & Greet picnic than appear here. I can't wait to meet all of you SoCal dialyzors, friends, family, Drs. clinic staff, AND doggies (great dog park there). See you in 13 days!!!!
Sunday at 6:42pm · Like · Comment



Ann Contreras If you're having trouble making Embassy Suites hotel reservations for New Orleans, hang in there. The Board is working on it.
Sunday at 6:38pm · Like · Comment



Brian Riddle <http://www.google.com/hostednews/ap/article/ALeqM5haeqSeNSWNkBJC00GEPJAKGKRWOw?dclid=613d58938a394096a8123170adcd1bb6>
The Associated Press: Amgen CEO got \$21 million in 2010 compensation
www.google.com
LOS ANGELES (AP) — Amgen Inc. Chairman and CEO Kevin W. Sharer received compensation valued at about \$21 million in 2010, a 38 percent increase from what he got the year before, according to an Associated Press review of the biotechnology company's proxy statement.
April 8 at 4:54pm · Like · Comment · Share
David Rosenbloom likes this.

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RockScar Love Designs

RockScar Love clothing celebrates the sexy scars of new life through organ donation! 10-20% of all sales goes to transplant community.
Steven D. Hirschauer likes this.
Like

Bucket List
groupon.com

100 Things to do in
Chat (8)

Storytelling for a Better Quality of Life

Faces of Dialysis

*...Real Stories of Living,
Loving, and Leading
Beyond Kidney Failure*



A wise dialysis patient is known to say:

Dialysis is not a death sentence — it's a life sentence!

How true! NxStageUsers is proud to be sponsoring Faces of Dialysis, where we hope true dialysis patients' stories will be told by pictures and supplemental comments. Each person will illustrate what life on dialysis is for them and could be for you. It doesn't necessarily have to be the debilitating condition many think. People are living "normal" lives with a good quality of life. Please look at the pictures and read the captions, whether you are a high government official or ordinary citizen; on dialysis or have Chronic Kidney Disease and pre-dialysis, or have no kidney problem at all; young or old of any ethnic background. Over 31 million Americans now have CKD. It's growing at epidemic rates. But dialysis, and optimal dialysis, is available to afford people a life which can still be very worth having. There is hope. Better than that, there are solutions.

Dialysis is not the end of life — it's just a new beginning!

Dialysis isn't the end of life; it's just a new beginning

Life is short, Break the rules, Forgive quickly,
Kiss slowly, Love truly,
Laugh uncontrollably, And never regret
anything that made you smile.
Life may not be the party we hoped for, but
while we're here, we should dance...

By Unknown Author

...or Snorkel



From 2010 Freedom Cruise

Tack Så Mycket

Rich Berkowitz

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www.HomeDialyzorsUnited.org