

The Sad Story of Juan and BAK

Juan: Born 3/28/00, Single mom with poorly controlled diabetes

Date: 28-Mar-00

Exam: U/S ABDOMINAL-LIM, PORTABLE

IMPRESSION: 1. LARGE THROMBUS OCCUPYING ENTIRE LUMEN OF THE LOWER ABDOMINAL AORTA, WITH SMALL AMOUNT OF FLOW VISIBLE AT LEVEL OF MID-THROMBUS NEAR THE RENAL HILA.

2. INTRAVASCULAR CATHETERS VISUALIZED WITHIN THE ABDOMINAL IVC AND AORTA WITH TIP OF THE AORTIC CATHETER WITHIN THE THROMBUS.

3. NO FLOW DEMONSTRATED IN COMMON ILIAC ARTERIES.

Entire lower half of body was dusky (no flow in lower spinal cord)

1 week of age

Date: 05-Apr-00	

Exam: U/S RETROPER-COMP, PORTABLE	
IMPRESSION: 1. LEFT KIDNEY SEVERE HYDRONEPHROSIS, QUESTION DUPLICATED COLLECTING SYSTEM. HYDROURETER IS SEEN TO THE URINARY BLADDER.	
2. THE RIGHT KIDNEY SHOWS INCREASED ECHOGENICITY AT THE CORTICOMEDULLARY JUNCTION WHICH COULD BE RELATED TO POST ISCHEMIC CHANGE VS. NEPHROCALCINOSIS.	

5 weeks old-recurrent UTIs

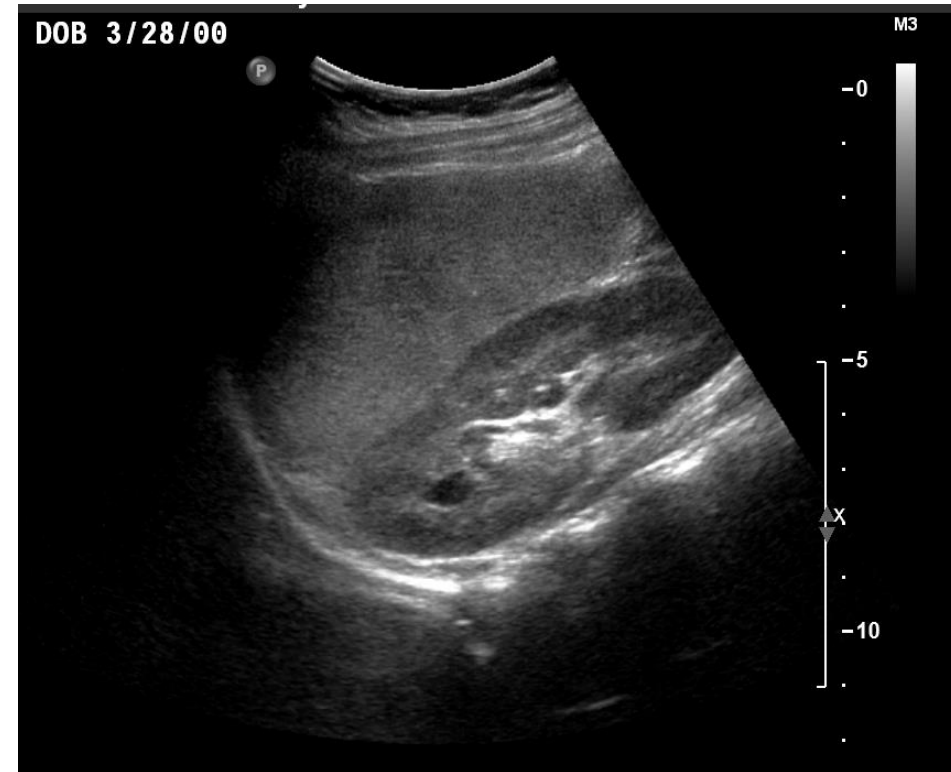
Vesicostomy-bladder dome was
yellow/necrotic

10 mo-stomal stenosis

redo vesicostomy, white scarred bladder

March 2005

Juan is 5 yo, vesicostomy, no UTIs



Mom insists that something needs to be done.
Can't go to school with vesicostomy.



Preop Workup:

May 2005: VCUG: Tiny bladder, 4-5/5 B reflux



His mother and the remainder of the family were well aware of how extremely dangerous this was and how multiple revisions would be necessary. They were also counseled actively on numerous occasions that failure to catheterize this reservoir could result in major medical problems including death. After understanding all these issues, the family wished to go ahead with the continent urinary reservoir.

Juan is 5 yo: May 2005

- 45 cm of ileum (not ileocecal as no fecal continence).
- 5 cm for ureteral reimplant that was intussuscepted into a W shaped bowel plate.
- Sewn into a sphere
- Appendix reimplanted via extravesical approach into ileum reservoir.
- Covered with omentum.
- Mom to cath

Juan is 5 yo, 7 mo postop. No surgical complications!
Irregular catheterization.



First major issue: BAK duped by well meaning, but incapable single mom.

May 2005 (5 yo): Reconstruction
Irregular cathing, no cath diaries
Waxing and waning hydro

2006 (6 yo): Urodynamic study
385 mL reservoir, good compliance, R 2/5 reflux

7/06 (6 yo): Mom: freq admissions for diabetic ketoacidosis
Foster mom: cathing and starting to self cath
Sometimes with foster mom and sometimes with aunt

7/07 (7 yo): Sono: mild B pelviectasis
2/08 (7+ yo): with foster mom, cathing regularly include x1 overnight
Volumes are 100-450mL

Multiple efforts at behavioral, psychological, social worker help

10 yo with somewhat better catheterization

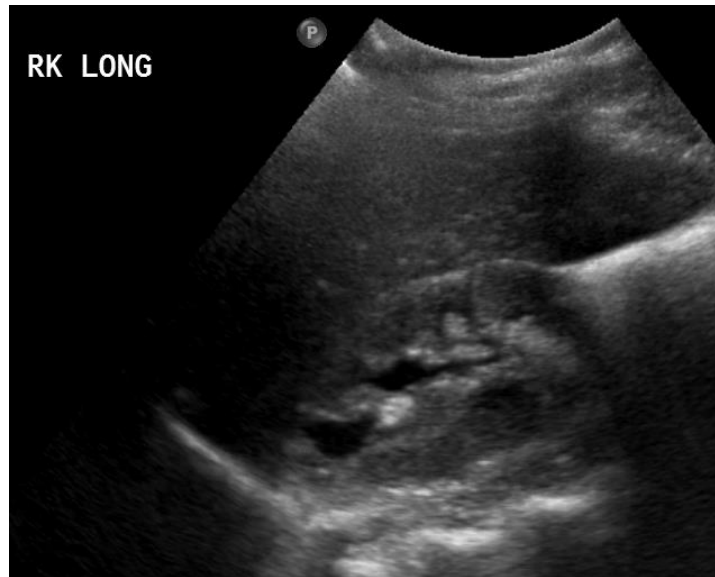


10/12/11: Juan is an 11yo in ED for possible UTI

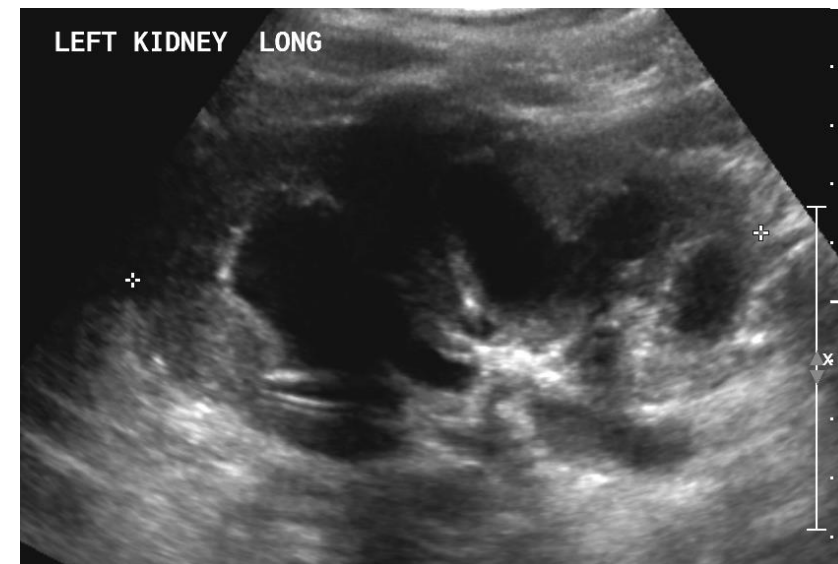
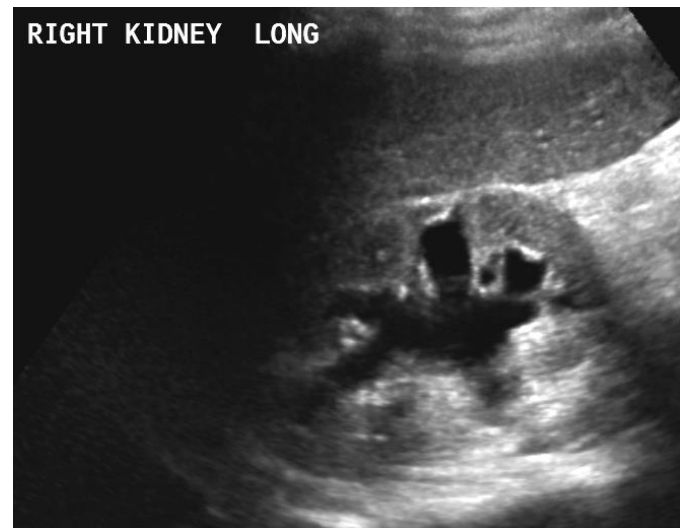


Sono of bladder: **1400mL** of echogenic debris!
Improvement p drainage
Creat 0.6 mg% p drainage

12 yo



2 mo later



2009: (9 yo) Mom passes away from complications of ketoacidosis
Adopted by Aunt. Caths irregularly, volumes up to 700mL

2011 and 2012 (11 and 12 yo)
Multiple ED visits with > 1000 mL in bladder and UTI
CT cystogram, no perforation but L reflux
Creat 0.7mg% p drainage

10/29/12 (12 yo)

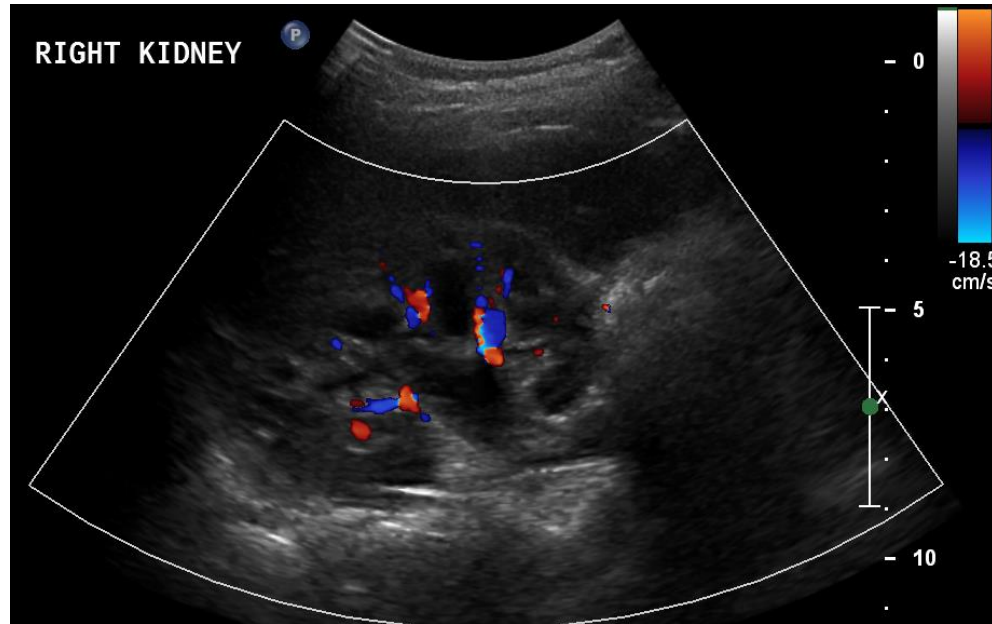
Family agrees to incontinent diversion.

Dissected the afferent limb of the reconstruction and brought it to skin as ileal conduit.

(left reservoir with continent stoma for future use when he is more mature).

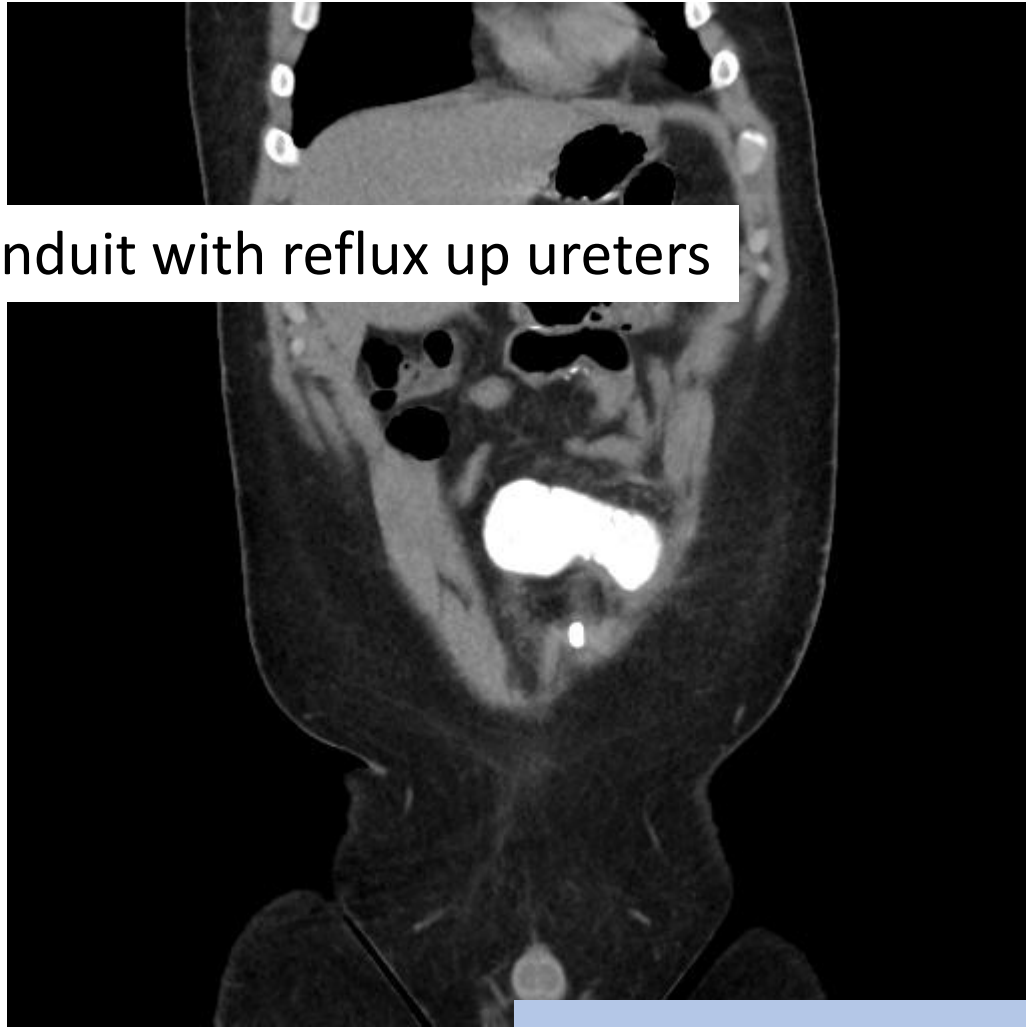
2nd major BAK error: Surgery cannot fix a psychological problem.

3rd major BAK error: Leaving continent reservoir in unreliable patient

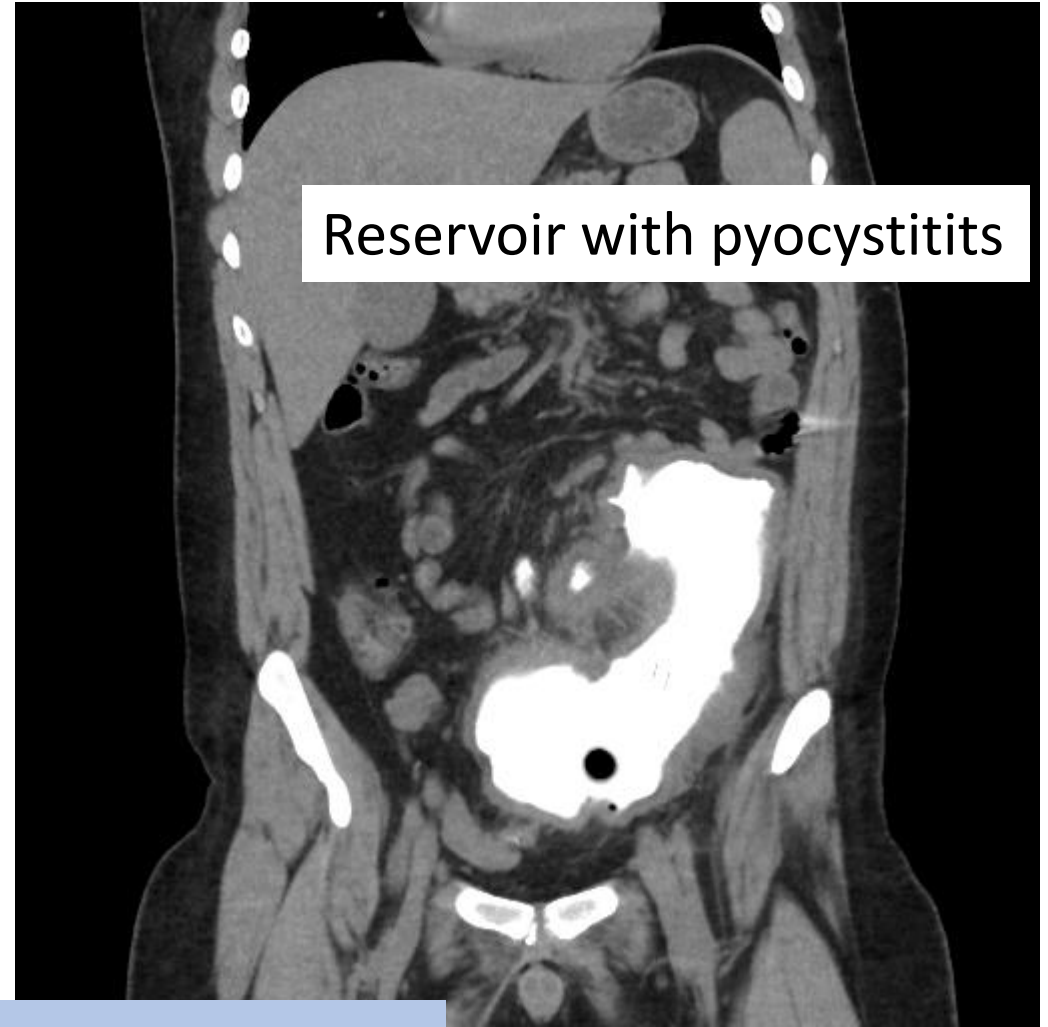


After conduit: Kidneys much better,
but.....**he keeps pulling his appliance off.....**

2018: 18 yo fevers, pyocystitis of previous neobladder!!



Conduit with reflux up ureters



Reservoir with pyocystitis

Solution: Send to your partner

Lessons Learned

Don't try to fix a psychological problem with an operation.

Behavioral issues trump technical success.

Use your brain, not your heart.