Contents

vim:linebreak:spell:nowrap tw=81 fo=tqlnr foldcolumn=3

OCT 2019 Dr. Bilbao

My notes show I tried to list contradictions: no symptoms of fat malabsorption, Colonoscopy (Dr. Wang at time didn't think inability to clear on 7-day liquid diet NOT big issue, did not connect to Ox when we discussed) Sitz test came back slow, but normal.

Parathyroid still high despite large doses of D3. ETC.

I do not see notes from the ACTUAL conversation. But she did not followup.

Early Jan 2020 PCC student calls

- I explain reg dds about to do cleaning.
- Next one is April-May.
- We agree to contact each other early MARCH. To schedule all the prelim appointments.

8 JAN 2020 email Dr: Wayne Wong re: MRI - Dr. Wei Wang (pancreas) Dr. Harbin>

8 JAN 2020

Dear Dr Wong:

Just spoke with Dr. Wei Wang (I'll call him Dr. Harbin - since that is hometown in China), who has a slightly different take on situation (hyperoxaluria + high fecal fat + low elease-1).

Has seen one patient with Pancreatic Insufficiency AND Bacteria overgrowth - said very rare.

Does not suspect chronic pancreatitis as a cause of fat high fecal fat or fat malabsorption, nor cancer or tumor.

Suspects low elease-1 may be FALSE, often diluted.

Felt PERT enzyme trial might give information, but he felt MRI could be more definitive as to pancreas health, at least to rule things out. Felt no indication for biopsy, an argument in favor of EUS (via mouth).

So we agreed on MRI. I believe he put the order in.

I would like Dr. Wang ("Dr Harbin") to stay in picture. He has some clinical experience with bacteria overgrowth and hyperoxaluria and generally seemed to be aware of some of the issues involved.

What do you think? jim >

JAN/FEB 2020 (or was it late 2019?) ... date unknown, call with Dr. Wang (GI)

(added 19APRIL2021) * Two cause hypothesis: fat malabsorption and bacteria in abdomen * Referral for hernia eval (rejected … not coverd) * Referral for EUS eval (this became NMR for pancreas) * Encourages enzyme approach; but I am skeptical that too few other symptoms. * Claims "success" means fecal fat drops by 1/2 (not just 10-20%). Told him Ox is my worry.

20 JAN 2020 - exchange emails with Julia C. (OHP) - resolution

Hi Julia C: Do either of these day/times work for you?-this Friday, 9 am-Monday, 9 am Please confirm by email or phone msg. The question I will ask you is what were you able to find out since our first (and only) conversation around Thankgiving?Recall there are two parts: (1) underlying actions of provider and (2) inability, at every level, for OHP contractors to do anything at all of any substance. Neither is close to any resolution and I feel the burden is now on OHP. Thank you.>

She leaves msg. on Friday at 3:42 pm! (Did I say 9 am?)

7FEB2020 – MRI, pancreas

Here are your test results per Dr. Wang:

MRI revealed multiple pancreatic cysts with pancreatic atrophy.

There was no evidence of pancreatic mass.

The findings are consistent with pancreatic insufficiency. -A little suprising!
(1) Thought he did not think PI or pancreatitis. (2) Cause??? Gallbladder stones? Blockage? (3) Why non-standard symtoms.

TWO problems: -pancreas health, don't let it get worse. -probably PI, fat malabsoprtion, start enzyme trial to see if oxalate drops?

ALSO, Dr. Mikay - every 6 months: kidney function and urine protein. sync with Litholink! (2 per year)

4 MAR 2020 – MRI, Dr. Wei Wang(pancreas)

-Begin Zenpep; see if reduces stool fat (to normal) and if urine oxalate (to normal). Esp if oxalate does not, revisit to see what is benefit of medicine.

-Details: Dr. Wang (pancreas) is cancer doctor and best to use email, not telephone appts since his patients need this. OK. Followup w/ endocrinologist or other Dr. Wang (GI) or email. Several times said oxalate, calcium are beyond his expertise. I do have FAT MALABSORPTION, PANCREAS INSUFFICIENCY and normal path is enzymes, followed by monitoring, repeat MRI in a year or so.

-Pancreas has 20-30 or more cysts and large. Maybe born this way; maybe had pancreatitis and that caused it (no pancreatitis now), maybe genetic (talk to family). 10% of population have a (one) cyst, this many is relatively rare. Has NO name. Will pancreas live another 10-20 years, yes. The cysts become large (size?) have squeezed the normal pancreas cells, compromising their function; not reversible. Severe atrophy. Shrunk available pancreas area.

-Cancer? No guarantees, but from MRI, which was right thing to do, these type of cysts usually benign. Redo MRI every other year to monitor. Can also remove pancreas! OR can have EUS through mouth to get biopsy. Monitoring or biopsy - he is neural.

-Zenpep. Should expect to gain weight (since fat remains in body); stool change. Reduced stool fat (to normal?) ; he hedged.

-Hyperoxaluria. Beyond his expertise. Period. Maybe another factor. All he is doing to studying pancreas and above is recommended procedure, information. (My 'theory' if fat gets absorbed, normally, then fat won't bind with Calcium on way to colon. Such Ca free to find with Ox.)

-Why no symptoms? Maybe my body got used it. So I asked what do we expect to happen? What is benefit? If no benefit, why continue with medicine? Ambiguous, but he understood.

-NEXT: start Zenpep; may need to adjust dose.>

5 MAR 2020 Dr Bibao, Topics for phone call >

Spoke with Dr. Wong (pancreas). Here are some topics I feel need discussion.

"Facts" Pancreas Insufficiency, Severe Atrophy Fat Malabsorption Enteric Hyperoxaluria Gallstones (small) Abdominal - descending

"Theories" Enteric Hyperoxaluria due to (1) Fat Malabsoption or (2) bacteria hangover or (3) some other factor. Nobody knows.

NEXT Zenpep OR xxxx Trial. "Success" if Stool Fat decrease by more than 50%, from 44 to 7- 22 g AND "Success" if urine oxalate decreases to <35. Discussion! If insufficient effect on UrOx, then what is benefit?

Need Discussion Litholink !! before/after trial Kidney Health! Many questions. Explain fat malabsorpton - no symptoms. Explain high PTH. Lupus antibodies? Prescriptons - review, decrease med? Abdominal hernia: problem since summer 2019. MRI - other organs? Pancreas - health, MRI everyother year.

Communications and Treatment Plan Too many questions unanswered. Lengthy delays. Stumble from one thing to next.>

11 MAY 2020 PTH, D3, serum Calcium>

Dr. Miyake says high PTH might be primary parathyroidism - see bone doctor . Drop D3 to 2000 IU/day; (14,000 IU/week).
(Will use 5,000 IU pills 3x till finish them).>

26 MAY 2020 Litholink, Labcorp - why no lab results?

-Litholink emails me latest report - thank you. -Am I am the only with problems getting reports from LabCorp website? No, others have complained. Aware things do not get fixed. Nothing Litholink can do, phone number for LabCorp 800-321-3862. (keep number - Labcorp website - has NO telephone number.)

1 JUN 2020 Dr. B has rec'd Litholink report and forwarded to others.

She doesn't give me any results (not sure she knows I have the report). Lousy doctor.

2 JUN 2020 New Primary Care - interview?

I am considering a change in Primary Care Physician and would like to talk with you, if you feel there might be a fit.

For my age (64), I am relatively healthy and try to follow the usual diet/exercise advice, plus regular health monitoring. Most of the issues I have appear to be well controlled, stable and not much of an issue.

One issue is not controlled: Hyperoxalura (high urine oxalate), and the associate risk for kidney stones and kidney function. There is still no confirmed diagnosis, and though fat malaborption is possible, there is also evidence more than 1 factor is at play.

I am not seeking an expert in hyperoxaluria, there are too few of these. Nor do I seek a physician to prescribe all the medicines, tests, referrals I need (or want). All Kaiser doctors can do this.

What I do need is a bit intangible. This is a relatively rare disease that can be tricky to diagnose; few professionals study; is often associated with conflicting symptoms (or lack of symptoms); plus has a large number of unknowns. Meanwhile the clock is ticking. I have adjusted to lifestyle changes (4-5L of urine per day for a little guy!), periodic tests, though not completely to the low-oxalate diet.

However, monitoring and a slow pace is not satisfactory.

My goal is speed up the diagnosis and treatment. What I do need is a medical advocate, an expediter, guidance in navigating medical uncertainties and medical decisions. Sometimes the holdup is me, and sometimes it is Kaiser. When it is me, it is because I do not understand the medicine, the thinking (show me the data!) or how this will lead to goal. Doctors have been quite wrong before; paths have led to more ambiguity; the years pass.

To put this on fast track I need to work with primary care physician who agrees.

If this type of challenge might appeal to you, and you have tolerance for patient raising (or seeking) data or questions, then I would be very happy to talk further to see if we are good fit.

Thank you for your consideration.

jim rothstein

11 JUN 2020 ? FALSE ALARM ... no heart issues

– chest discomfort gas, heart, other? for past several days. ZERO aerobic exercise (covid-19) and brisk walk to Amazon led me to freeze, discomfort along the way ... need to make repeated stops. But recovered. However, discomfort seemed to linger. – Kaiser advise nurse says go to ER. Now. – Drive to Westside. 1st class service! @ 4am; people with nothing to do? ekg - normal; blood tests - normal; chest xray - normal (ie no TB issues). – Followup with Dr. H on Monday 16, June. Seems all normal. Urges 'stress test' – will do. – He checks EAR, SKIN ... psyorisis ... more meds coming for SKIN. LEFT mineral oil to remove wax buildup. Then shower. – Show him above letter; says Bilbao one of the smartest. ; not his job to make doctor suggestions; all Kaiser doctors great; just call to change;

16 JUN 2020 Miyake punts .... Enter Dr. Carl...

– Nephro calls, tele appt with Dr C in July; apparently discussion bet he and Miayke; since Dr. C had academic appointment (so?) he will now handle my case. OK. – Litholink, time from 1st request (fall '19) continuing till now, can we go ANY SLOWER?? If i didn't have results myself, none of the doctors seem to feel I know results in any reasonable timeframe. Just low priority for all.

2 JUL 2020, Call w/ Dr. Lam, new Urologist

- seems to question whether have enteric hyperoxaluria
- PLAN; contact him after Dr. Call.
- kub - often useless, suggest ultrasound, then CT, note: ultrasound can sometimes exaggerate size of stones
- Asked hydrothiazide (told him K+ problem)
- normally, defers to nephrology but we discussed transition bet Mikayke and Dr. Call (I had nothing to do with it)
- strongly endorsed Dr. Coe (read his papers: clearer)
- raised Q about **renal hypercalcemia** (high serum Ca).... ("calcium leak" in kidney and mentioned PTHT)
- seemed to have good investigative attitude, practical knowledge

23 JULY 2020 Dr. Carl - nephrology - telephone

- Seems to have done his homework, well-prepared. Lengthly phone call.
- Seemed to understand my hesitation re: pancreatic enzymes: what problem trying to solve? Will this reduce urine Ox? What improvement in GI are we expecting w/ enzymes, given lack of symptoms now?
- His focus seemed to be avoid stones. My focus seems to be high UrOx.
- He admitted to have seen patients on dialysis due to high UrOx (without stones.
- His idea: perhaps what is normal for others, is not my normal. In particular: PTHT, Urine Ca, UrOx. He also spoke with Dr. Lam today, and sounds like some agreement:
  - get CT to see if ANY stones, even small.
    - if none, then we might be able to assume that my current numbers are normal for ME.
    - I was hesitant. Need to learn a bit more about "everyone's normal is differnt" and that high UrOx is not such a major concern for ME.
- ALSO, suspect parathyroid may become OVERACTIVE (happens). Has seen its **removal** lead to NO stones.
- WILLING to talk to Coe, Liske et al.
- Wants to talk again in 1 month. My position is (or should be) open to almost anything, just want to see some evidence doing A has worked in others and nonot guessing.

***

August 5, 2020

Dear Dr. Lam and Dr. Carl:

First, greatly appreciate your telephone calls and time and offers to assist. Apologize for delay.

You have brought up ideas that various factors might be related to hyperoxaluria and recent high PTH levels. I would like to learn more specifics. In particular, agreeing to a plan to systematically test your ideas would be a very big help. I want to understand the significance of the various anomalies uncovered in recent years.

In no particular, order here is my list:

- Urinary Oxalate.

- Pancreas heath, pancreatic atrophy, stool fat.
- Kidney health, long-term (even if absence of stones).
- Parathyroid health.
- GI, including possibility of bacteria (hernia) + fat malabsorption.
- Utility of various prescriptions/supplements.

Separately, I will prepare graph of 24-hour Urine Oxalate since 2014 so you can see the wide variation.

I am also trying to find records of Thiazide (1999-2009?), and the low Potassium and bilirubin results, till a doctor terminated the prescription.

Reference: [kidney oxalate] (https://www.kireports.org/article/S2468-0249(18)30171-2/pdf)

- KCitrate - daily dose
- Vitamin D3, Now: ~15,000 IU per WEEK.

- Vitamin D3, (2017? - spring 2020): 27,000 IU per Week, per OSHU to correct parathyroid (did not work).
- Calcium Citrate Supplement - ~1000 - 1200 mg per DAY, w/o D3 (plus dairy, dietary sources). Is this working?
- Low Salt Diet - >20 years. (not perfect, but careful.)
- Low Oxalate Diet - tried, but very difficult. careful, but not fully compliant. (healthy foods often rich in Ox); Anecdotally, urine ox is high EVEN if I refrain from all oxalate. Is this working?

Here is [Dr Coe's website:] (https://kidneystones.uchicago.edu)

Thank you again.

jim rothstein

September 1, 2020

Dear Dr. Lam and Dr. Carl:

Anticipating our phone conversations schedduled for this month, I am collecting a few questions on my mind. This is supplement to my August 2020 note to you, but in the form of questions:

```
Risks of abandoning any pretent of low-oxalae diet and return to vegetarian
    diet rich in pulses (lentils, beans) and nuts (plus the usual good
    vegetable)?

    Why?    I was heathliest on this diet; lowest lipids, glucose, best stool,
    lowest weight etc.   The diet seemed to match all the modern dietary
    information, which low-oxalate tramples upon.
```

You have brought up ideas that various factors might be related to hyperoxaluria and recent high PTH levels. I would like to learn more specifics. In particular, agreeing to a plan to systematically test your ideas would be a very big help. I want to understand the significance of the various anomalies uncovered in recent years.

In no particular, order here is my list:

- Urinary Oxalate.
- Pancreas heath, pancreatic atrophy, stool fat.
- Kidney health, long-term (even if absence of stones).
- Parathyroid health.
- GI, including possibility of bacteria (hernia) + fat malabsorption.
- Utility of various prescriptions/supplements.

Separately, I will prepare graph of 24-hour Urine Oxalate since 2014 so you can see the wide variation.

I am also trying to find records of Thiazide (1999-2009?), and the low Potassium and bilirubin results, till a doctor terminated the prescription.

Reference: [kidney oxalate] (https://www.kireports.org/article/S2468-0249(18)30171-2/pdf)

- KCitrate - daily dose
- Vitamin D3, Now: ~15,000 IU per WEEK.

- Vitamin D3, (2017? - spring 2020): 27,000 IU per Week, per OSHU to correct parathyroid (did not work).
- Calcium Citrate Supplement - ~1000 - 1200 mg per DAY, w/o D3 (plus dairy, dietary sources). Is this working?
- Low Salt Diet - >20 years. (not perfect, but careful.)
- Low Oxalate Diet - tried, but very difficult. careful, but not fully compliant. (healthy foods often rich in Ox); Anecdotally, urine ox is high EVEN if I refrain from all oxalate. Is this working?

Here is [Dr Coe's website:] (https://kidneystones.uchicago.edu)

Thank you again.

jim rothstein

F 4 SEPT 2020

Telephone appt with Dr. Carl (nephrology). Didn't talk to GI. So recommedaton is CT and if NO tiny stones, then conclude this level of UrOx is good baseline with me.

Ugggg .... Next 45 min? Get a F* inclusive plan; show me data; account for pancreas, hyperox, etc etc ... repeat and repeat. Going nowhere. Don't want repeat it all here.

M 7 SEP 2020 DDS, OHP complaint

See email. Zero response from OHP for March 2020 termination from OHSU.

21 SEP 2020 Dr. Lam, urology

- See note I sent (pdf). Need for consensus. He was not as prepared this mtg. Says he spoke to Dr Carl, but seems like I am repeating myself often and do not move forward very much. Did say PTH is not make worry, b/c my serum calcium is OK (except for one point).

21 SEP 2020 DDS, ODS Cathy, sees nothing in my record. Says, OHSU must

give reason. I read her the email (Mar 9 2020). Said OHSU now beginning to take patients again (Covid), but I argued my termination was nothing to do with Covid and arbitrary - long history. She calls OHSU, I am on hold... long. (total call ~ 56') Then she gets back and says she needs to research this 5-7 days. OK. Sounds like she didn't understand whatever OHSU said to her. Says she does not want to give me incorrect info. ?? MY reply: PLAY BY RULES: If there is supposed to be dismissal letter, why not sent? INVESTIGATE does not mean telling whatever they say as truth and CLOSE. Too bad if they didn't like that I went after them after the first time they did this. Cathy seemed to undrestand. Wanted me to make appt with another ODS DDS, but I am not sure if that rules out returning to OHSU (assuming things can be smoothed out).

Voice (22 SEP 2020) from Cathy: "You were dismissed due to some behavioral difficulties. And if you want to find out more information..." Dismissal letter coming (now?) That's an invesigation? Specifically told not to believe them anymore than she should believe me: investigate! Each time story different. This is just a madeup story!

Sat 07 Nov 2020 Kaiser, DDS, Cleaning

Kaiser cleanings are fast! (1 hour) 3 month cleaning cycle, “perio maintenance” This is NOT “deep cleaning”, which requires anesthetic & is ONE quadrant per time. I do NOT need this. CLAIM: Manual cleaning is just as good as with water drill. Due to Covid, manual is safer for dentist.Younger hygenists are taught water drill CLAIM: ACT (fluoride) is good. But Lisertine does NOT have benefit. It does kill bacteria, but when bacteria returns it uses dead as food. Hygienist didn’t think necessary to continue. CLAIM: BUTLER has better floss that won’t shred. CLAIM: G-U-M little brushes - to poke - are very good; but G-U-M tool that slides between teeth is too smooth, like GLIDE.

T 09 Nov 2020 kidney, Dr Carl

- Since Litholink delayed (nobody watching!), Dr Carl moves telephone appt to late Dec. Didn’t I tell him reluctant to change date; going into queue always adds another 6 weeks; believe he said he would help.
- So wrote yet another note to him asking him to confirm that purpose of Dec mtg to present me a plan (see letters).
- Then, unrelatd, ultrasound people call me to schedule. OK, but they say must be done in late Dec. OK, so I call Kaiser nephrology nurse Laura … what is going on? She checks and says Dr. Lam ordered it!.
- Give her message: people coordinate! why so hard? And made it clear to her that I expect Dec mtg to be consensus. aya … justing wasting my time.
- Why so difficult for medical profession to work together?? Still nothing from Dr. Carl confirming Dec mtg. **Why so hard?**

Patient information/comments below.

- Also pt asks Litholink to check these doctors are properly authorized to ORDER and RECEIVE reports Litholink: Kaiser NW: Dr. Denise Bilbao; Dr. Daniel Carl
- PLEASE NOTE: Pt has NO official diagnosis. Many doctors. Suspected enteric and fat malabsorption. However, symptoms often contradict diagnosis. Pancreatic atrophy is confirmed. “Theories” range from fat malabsorption, PTH (high), bacteria issue in abdominal hernia, low calcium, “you just have it”, “your body may have adjusted and this is now normal”. Pt asks if certain diet is not cause?
- PLEASE NOTE: Dec 23, 2020 - Kaiser doctors to present to Pt consensus and comments on ALL the above possible causes. Provide specific options and medical references to guide confirmed diagnosis and then actual treatment.

Page 1

- No comments.

Page 2

- No comments.

Page 3 – Interpretation of Laboratory Results

- No bowel disease or bowel surgery. Your NOTES are Correct.
- High protein intake (PCR is high, 1.4g/kg/d).

  Pt ate 1 can sardines (in 2 servings), nuts, beans, yogurt, cheese and too much ice cream - during test and 36 hour preceding. Pt surprised this is high protein and now asks for doctor’s guidance.
- Pt maintains **food intake log for almost all 24 hour urine tests** (since

2014)

- Low calcium diet

  Pt skeptical. Pt says diet rich in Calcium (dairy, sardine bones, low-oxalate veg) PLUS takes CaCitrate supplements.
  Patient open to “clinical evaluation”.
- Low Oxalate Diet.

  Pt unable to maintain very low Ox diet, considers too unhealthy compared to normal diet. Also, results from 2014 indicate extremely low Ox diet did not bring UrOx into normal range. Has been through ‘dietary consult’ but says will gain weight and eat unhealthy foods or healthy foods (eggs) in unhealthy amounts.

  Pt is open to diet changes – if done if controlled, precise manner. Pt willing to minimize all dietary oxalate, below tolerable, for testing purposes. Pt wants to know how long BEFORE beginning 24-hour urine test to refrain from Oxalate.
- Change diet repeat 6-12 weeks. Pt willing to do. Again asks for pre-test TIME needed for high-protein or high oxalate to clear urine.
- Primary Hyperoxalura -

  Pt has been tested (Mayo Clinic trial) and urine tests (Ore Health-Science U OHSU chromatography) negative. (Exact details unknown.)

- Urine glycolate and glycerate measurements. DNA testing. Pt has no objection.
- Low Urine Citrate.

  Pt confirms adherence to KCitrate 4 x 10MET per day (compliance > 95%) and CaCitrate 1000mg -1200mg per day (compliance > 95%)

  Pt is looking offline historic Urine Citrate 24 levels - PRE KCitrate. Feels certain that in 2014 level was low that KCitrate added. Recalls results calibrated with 3 x 10 MET before doctor decided to go with 4x10 MET per day, unchanged to this day.

  Latest eGFR = 53 (Eastern European origin)

  Pt willing to increase dose and **retest in 6 weeks, as suggested** (early Jan 2021).
- High Urine pH Pt says always high; assumed it was to high vegetable intact (esp Kale, Bok Choy, Broccoli) Often with every meal.
- Alkali Potassium Citrate
- Urine Uric Acid Pt says pre-Allopurinol, **Urine Acid 24 was as high as 950 (7/29/14)**

Page 5 - Serum Chemistry

- Race Pt is Eastern European descent.
- Serum Calcium
  Pt asks why all Serum Chemistry missing for 23 NOV 2020 test? Kaiser Lab (same date) report serum calcium 9.4 mg/dL and serum creatinine 1.40 mg/dL (eGFR=53)

Page 6 - 9

- No comments.

NEXT?

- Raise KCitrate to 5 x 10 MET per day, retest early Jan 2021. Kaiser agrees?
- Can minimize diet UrOx and take care with protein. Compare to Nov 23 results.

22 DEC 2020

Summary: Telephone Conversation - Dr Carl and Jim Rothstein

VERSION 0.0002

Changes from 0.0001
- see PTH Elevated: May 2020 reduced D3: Related to serum calcium drop?
- GI/Pancreas: notes from Dr Wei Wong (Pancreas - MRI), Dr Wayne Wong (GI), Dr Lam (urology - PTH)

If anything below is incorrect, please let me know right away.

Appreciate if henceforth all Kaiser doctors refer to latest version of this document so that we are all on the same page.

By topic, not chronology, this is my understanding:

Secondary Hyperoxaluria.(responsible Dr: Dr Carl).

- Highest Priority problem. #1 ailment.

Litholink,

- repeat 24hr urine with KCitrate at 5 x 10 MET vs 4 x 10 (Nov 2020). (order: Dr. Bilbao, results: Dr Carl?) **PT DEADLINE: 2nd week January.**
- This should not delay anything else in this document. This in parallel to other activities.
- Also, please review my reply to Litholink comments. I would like that reply and questions to be part of this summary.
- Please see question re: high protein diet and low calcium diet (Pt skeptical). What corrective changes, if any, to make? **Pt needs guidance.**
- Goal: Rule out as many “possibilities” as possible, so Dr. Asplin (Litholink) is able to help us zero on important data.

Urine Oxalate (Dr.Carl)

- Investigate: How much does UrOx vary in pts with secondary hyperoxaluria? (See Coe)

Discussion with outside experts. (Dr Carl).

- Absolutely welcome.
- However: I would like to Kaiser doctors to be on same page first. Not case now. Outside experts should be reserved for the really hard, focused questions.
- Original plan was to do this mid-January 2021. Pt hopes everyone will cooperate to get this back on track.

Pancreas, GI, Fat Malabsorption (Dr Wayne Wong, “Dr GI”)

- Pt has numerous Pancreas, GI questions, not all covered here.
- Pt to make telephone appointment w/ Dr Wayne Wong and others ??
- As of late 2019, pancreatic insufficiency (PI) and fat malabsorption (FM) very suspect, possible bacteria in abdominal hernia (AH). Dr GI (Wayne Wong) recommended enzymes for PI, with expectation that 72 Stool Fat would decrease by 50% or more. Effect on UrOx unclear.
- Pt insurance (OHP) rejected Dr GI hernia referral.

- Early 2020, Dr. Wei Wang (“Dr Pancreas”) recalls seeing only one other case of both PI and bacteria: rare. Without symptoms, possible not PI.
- MRI confirms Pancreas Atrophy (PA), has 20-30 or more cysts and large (rare to have more than one!) and consistent with PI. No need for EUS, though I can; repeat MRI in 2 years, monitor. No pancreatitis, but I DID HAVE IT. (Pt has no recollection of such, except for lactose intolerance age 19-20). Normal recommendation is enzymes.
- As to why no symptoms of PI, Dr. Pancreas said “your body may have adjusted”. No opinion related to hyperoxaluria. (Ref email and notes, 8Jan 2020 and 4APR

2020)

- Zenpep. Should expect to gain weight (since fat remains in body); stool change. Reduced stool fat (to normal?); he hedged. Also may need adjust dose.

- QUESTION: health of each organ? Why so many do I have “rare” situations?

- Please NOTE: To understand Pt thinking, please give weight to following:

  When Dr. Wong said “clinically not possible” and Dr Miyake said “unique”, I stop listening. You have not seen this before. Perhaps a failing on part. In math once the proof shows a contradiction or uniqueness, you are done. More talking won’t get us anywhere.

PTH Elevated . (Dr Lam?)

- Back burner. Mildly elevated. Monitor.
- Not related to hyperoxaluria.
- Review if Serum Ca rises.
- (**26 DEC 2020: D3 supplementation reduced May 2020, from >25k IU to 15k IU. Explains drop in serum Calcium?**)

Calcium, Calcium, Calcium (Dr. Carl?)

- Off the table. Kaiser promoted this for years.

- It is not the fix. Calcium intake + supplements seems more than adequate (to Pt).

CT scan, kidney stone burden.

- Back burner. Can reconsider if (a) evidence shows this snapshot is good predictor of future kidney stones (1-10 years) or (b) medical situation changes.

29 DEC 2020 U/S, 1 stone

Fri 08 Jan 2021 misc litholink, dr carl, lab blood draw

Spoke at length with Tina Rybolt (630-361-0427) handles dr approvals and knows the process. Explained ordering and blood draw. (See 2021_procedures_litholink ...)

- Next 24-hour litholink as soon as kit arrives
- 5 x 10 MET for KCitrate (b/c low)
- VERY LOW OX DIET .... no nuts, no beans .... (eat ice cream and bread)
- EASY on protein ....
-

Mon 11 Jan 2021 EAR, dry skin,

- Left ear blocked past week, barely even hear in left.
- Nurse - BOTH blocked. Uses water to flush out both - disgusting brown globs.
- There are TWO problems:

Inner Ear, ie channel - nothing goes in (see Exception)

- problem is wax; natural; nothing I can do.
- no mineral oil, no q-tips (makes it worse)
- periodically return to have flushed out!
- Why not a problem before? (Actually, it was problem ~ 1-2 years ago)
- **Exception** if ears blocked, 3 days BEFORE returning for cleaning, drop mineral or baby oil into channel (softens the mass, to make extraction easy).

Outer Ear, ie NOT channel, skin very dry.

- Use a lotion, Vaseline, “acquafor”
- If bleeding from outer skin, SEE PROVIDER.

2 hours after nurse cleans ears, LEFT ear feels clogged again. Hearing is fine, however.

Tue 12 Jan 2021 Questions for Dr. Asplin

14 JAN 2021

Dear Dr. Asplin:

We corresponded in May 2019 re: Hyperoxaluria. I am Litholink patient with secondary Hyperoxaluria with no diagnosis. Dr Daniel Carl, a neprhrologist at Kaiser in Portland, Ore, will contact you shortly. I hope you will have time to review recent Litholink reports with him and also discuss my questions.

Thank you.

23 NOV 2020 - Collection and Litholink Report
13 JAN 2021 - Collection (repeat, increased KCitrate, very low diet Ox, low protein)

1. Litholink report: 23 Nov 2020 collection
   You should have my comments on this report, in particular references to high protein diet, low calcium diet, adherence to KCitrate, urine pH, and of course UrOx. Appreciate if you review.

   Note: May 2020 Vitamin D3 supplement decreased from 25,000IU per week to 15,000 IU per week. (PTH did not drop with higher dose.)

2. Variation in UrOx? Please see Graph.
   Several values are from Litholink, the remainder from Kaiser Lab. Please comment on variation in values. Can you refer us to a reference which discusses variation of urine oxalate and significance?

3. Diet - Contribution to UrOx?
   To study effect of dietary oxalate on urinary oxalate, is it possible to set up a prescribed series of diet and sequence of 24-hour urine tests? Clinical trials appear to use this method. Can you refer us to a reference to describe how to do this?

4. Because the urinary oxalate is so variable, pt feels can not single out any one value and conclude “we are heading in right direction” or “improvement over last time.”

   Do you agree? Can you suggest a testing procedure?

5. Dr Carl of Kaiser will ask you about pancreatic enzymes. Please understand Pt is skeptical because symptoms of fat malabsorption are missing: no diarrhea, no malnutrition. Will pancreatic enzymes affect urinary oxalate and if so by how much? Again, do you have reference?

There are many more specific questions, but guidance on these topics would be wonderful start.

Thank you.

jim rothstein

Attached:
* Urine Oxalate 2014-
* Urine Citrate 2014-
* Serum Calcium 2014-

Fri 15 Jan 2021 Blood labs, Q to Asplin

- Asked Dr. Carl to contact Dr Asplin, all my questions, comments are posted.
- Kaiser labs come back, a little too good: GLU 97, eEFG = 58 and THIS while on lousy low-Ox diet, low protein and plenty of sugar.

Tue 26 Jan 2021 Dr Cynthia Tai(Donna: 503-786-1158), Dr Carl seems just lost...

- email from Dr Carl: did I do 24-urine test? No response to any of my earlier emails. Not on the ball. (see correspondence for my return email.)
- call Dr. Tai (head of Nephrology); last spoke ~ April 2019; need to have another discussion:
  - **Kaiser can’t handle this.** You can monitor, but 6+ years and many, many doctors.

- **Need to admit that.** Then need referral outside of Kaiser, OHSU. Step ONE Admit you not set up to do this. Maybe too busy; Maybe problem falls inbetween what you guys do.
  - No urgency.
  - No team. Stop saying it. Left and Right never on same page.
  - I document: Still never on same page.
  - Tiring for me; must be tiring for you.
  - Endless breaking in new doctor , which takes literally foreever to get upto speed (I often give up …. then things sit for months/years.)
  - Primary Care doctors NOT able to coordinate. Stop saying this.
  - Never stay on schedule.
  - Often do not even follow-up or not follow-up to each Q.
  - Kaiser may be able to do the care; but you CAN NO LONGER take the LEAD. **You must admit this.**

WED 27 JAN 2021 Mellissa calls me (503-314-5926)

- Overseas different Nephrology offices.
- Listened; seemed sympathetic; will talk to Dr. Tai; who knows?

Thu 28 Jan 2021 Dr. Tai calls - leaves no number

- Sounds like ‘gee what’s going on’.
- I call Melisa (1) EXACTLY kind of problem past (2) leave a damn phone number (3) if she doesn’t know what is going; she needs to get up to speed. Said thanks and hung up.
- Dr. Tai calls later; leaves msg. Out tomorrow; in hospital today so can not give any phone b/c moves about (is this BULLSHIT? Is this how doctors communicate with each other … hit and miss??). Doesn’t sit at desk. Call Melissa and schedule time.
- I do not want to play this GAME. 1000s of emails. Dr. Tai doesn’t realize; she is END_of_LINE. If she does not agree with my conclusion (Kaiser can NOT do it) or disagrees with my analysis; so be it; nothing I can do. Talking to her IS NOT GOING TO CONVINCE anyone. The data stands for itself.
- My purpose is to (1) get Kaiser to admit FAILED and (2) plan with me to get in front of a doctor (elsewhere) who DOES have sufficient experience to handle OR guide Kaiser. But outside person must be in lead.

Tue 02 Feb 2021 - Call with Dr. Carl; his call to Dr Asplin, UrOx = 49 !

- 60 minutes, Dr Carl has NOT read my notes & Q prior to Asplin; still progress …. Details below:

23 FEB 2021

VERSION - FINAL

This document:

- Telephone Conversation - Dr Carl and Jim Rothstein (02 FEB 2021)
- Feb plan
- Still open/unsure (post-Asplin)

- Questions for Dr. Lieske (Mayo)

See also:

- Litholink Report Nov 2020
- Litholink Report Jan 2021
- JR response to Nov 2020
- JR questions to Dr. Asplin: 14 JAN 21

If anything below is incorrect, please let me know right away.

The purpose of this is to be sure we are all on the same page. I would be grateful if Dr. Lieske is willing to temporarily provide guidance and/or options.

The intermediate goal is a correct diagnosis of why I have hyperoxaluria. The longer term goal is how to minimize UrOx itself and protect against associate risks of excess oxalate. Can we see measurable results by June 1 ? ***

This list below is by topic, not chronology. Some items may be appear as repeats because I either did not grasp the answer or have questions. The first several refer mostly to Dr. Asplin (Litholink) and then to Dr. Lieske (Mayo)

1. Where we are now?

- Latest Litholink (with very low dietary oxalate) suggests these paths:
- DIET: Is bulk of hyperoxaluria explained by DIET?!

- Remainder of UrOx, is there a hidden genetic possibility?
- GI/Fat malabsorption - clearly I have problem here, but how does the data explain UrOx?
- There have been other suggestions, ranging from calcium, PTH and so forth;

2. Next step: To verify latest Litholink:
    1. Repeat asap with SAME diet
    2. Dr. Carl to obtain OHSU records that ruled out genetic.
    3. Jim to collect prior diet records from 24-hour urines.
    4. Stay with 4 KCitrate pills; UrCitrate did rise with 5 pills, but 4 seems adequate. Jim to supplement citrate with lime or tamarind (ample citrate?).
    5. Since protein can also raise UrOx; jim to maintain protein intake ~ 1g/1kg or about 70g per day. (1 chicken breast = 30 g).
3. Still unclear or open: (post-Asplin)
    1. Proper D3 supplement? Is 15k ok (vs 25K) per week (PTH; Serum Ca) See Asplin Letter #1.
    2. Dr. Asplin (Litholink) said variance in UrOx numbers are within ‘normal’ for secondary hyperoxaluria. Reference please. Do we agree that because of this variation is **not useful to reference one data point” or the last data point? Asplin Letter #2
    3. Calcium: Is there agreement, low-calcium diet comment (Nov 2020) is not correct.

4. Calcium: I do not see benefit of all the supplemental Calcium. Yes, I know it is standard first line of treatment. How to quantify benefit of this Calcium and confirm its necessity? [1]
5. Dr Carl of Kaiser will ask you about **pancreatic enzymes**. ? See Asplin Letter #5. References?
6. DIET Prescribed Ox diet used in clinical trials? See Asplin Letter #3.
7. Ur Uric Acid. Why do I need Allopurinol? (see Nov 20 Litholink and Comment Litholink Page 3)

---

6. Assuming UrOx results are reproduced, Dr. Carl to contact Dr. Lieske. Goal is mid-February.
7. On the table for leview with Lieske, the various strands:

    1. ALL of the above (Believe he has content for Kaiser and Litholink records)
    2. DIET?!
    3. Fat malabsorption/ GI issues
    4. hidden genetic
    5. Other, whatever is relevant to him: PTH, Calcium, hernia ...
    6. Everything else.

    CONSENSUS PLAN means to me a systematic way to narrow down all the theories and surprises and appointments with doctors in every specialty. "Everyone on same page." Or, Dr X knows what Dr Y is thinking/ordering.

    Every doctor entitled to his/her thoughts, of course. But by "PLAN", I mean we have way of evaluating in reasonable timeframe, so we reduce, not increase, total open issues. Can Dr. Lieske help identify the problem. **What steps to be done, in series or in parallel, and in what order.**

8. (Example: not consensus) Pancreas doctor suggested that despite pancreatic atrophy my body "may have adjusted". Lieske believes this? Reference?

    Avoid taking a year or more to investigate.

12. Calcium: Is patient candidate for Ca tracing?
13. Comment. Eliminating diet oxalate is NOT an answer.

Misc other questions (not for Lieske).

15. Diet? Sardines with bones. But with or without skin??
16. Fructose ... how much is too much? (Ex 2-3 oranges /day and role in UrOx)?
17. Lime ... benefit?
18. Coe (Chicago) work with dietian. Benefit? First I want to know what portion of UrOx is due to Diet.

[1] For many years, Kaiser continued to recommend Calcium, more Calcium without observing any benefit.

Thu 11 Feb 2021, DDS - cleaning

- FLOSS - purpose is disturb bacteria, so less concentrated. NOT to clean.
- Rear Teeth - OK to use GUM - extra srong flossers (not regular floss) if regular floss streads.
- Mouth Guard - clean with soap and special brush. Toothpaste (fluoride) is actually too abrasive and weakens material. Use SOAP!
- Jennifer works to 5 pm. Other hygienists work later (ie take WES train in time to arrive 4:30 pm.) At least 2 use manual scraping.
- Disclosing tablet? Mostly for students to see ;

Sun 21 Feb 2021 Litholink, end 24-hour Collection, not very low-Ox

- Kaiser Lab a little confused about doctor's order.
- DIET is NOT very low oxalate; some nuts, avacado.. less than 'usual' but NOT LOW.

Tue 23 Feb 2021 will give heads-up to Lieske that Dr Carl may call.

- Fri Barb writes back asking Litholink, gave her last 4 . ## Sat 27 Feb 2021 STONE passes, ~2-3 mm (at most)
- black, hours before penis feels something; no blood no mess. Couldn't fetch the stone.
- Dr. Lam replies .... inline with 5 mm stone from U/S (U/S exaggerate

late FEB 2021 Dr. Carl is "out-to-lunch"

- clueless whether he is getting Litholink (I get 10 days later, never heard from him). Disappointing. This guy not reliable; not on top of things ... fortunately Lieske may be in picture:
- Neprh calls for late Apr appt; now is early March ... total bs.

Thu 04 Mar 2021 Lieske replies: phone call?

> To me this looks dietary in nature. I think he's on a very vegan leaning diet based upon the patterns in the urine (high potassium, citrate and pH with the high oxalate, plus suppressed urine ammonium. We could offer him a video visit if he likes. John

Tue 09 Mar 2021

Dear Barb: Attached please find: 1. Very latest Litholink report (Feb 2021) 2. Current prescription list 3. List of **prior** hyperoxaluria suggestions.

09

MARCH 2021

Rothstein, James
23 DEC 1955 Mayo # 12261030

For Dr. Lieske - for use during phone call (Will not make sense otherwise)

PRIOR Hyperoxaluria theories

1. Take more calcium
2. “You just have it” [hyperoxaluria]
3. Take more D3 to reduce PTH [didn’t]
4. Surgery may fix PTH (and hyperoxaluria ?)
5. If ‘stone burden’ is low (via CT scan), conclude hyperoxaluria is ‘normal’ for you.
6. “clinically not possible” [fat malabsorption without diarrhea]
7. “unique”
8. “Your body may have adjusted” [to pancreas atrophy without diarrhea]
9. Variance in UrOx is in ‘normal range’ [for people with enteric hyperoxaluria}
10. You may have hidden generic factor, not one of common ones.
11. You may have TWO causes: pancreatic atrophy AND abdominal hernia bacteria, which just balance so no diarrhea, no malnutrition, no symptoms.

FACT: Colonoscopy prep increasing difficult (over years) to completely empty. FACT: Last one: 7-day liquid diet; not empty; ~36’ to empty during procedure. FACT: At time, GI doctor nothing amiss and that I was just “slow”. FACT: Much later, came two-cause hyperoxaluria theory: so patient not sure if possible or just another theory. Dr suggested pancreatic enzymes, but patient unclear benefit, how prove or disprove theory, or affect hyperoxaluria.

Thurs 11 Mar 2021 spoke with Dr. Lieske

- See my notes on G- docs. Seems promising; has seen;
- Wants diet 100 mg Oxalate (crazy!) + enzymes.
- Begin Zenprep (all enzymes are NON-generic)
- NOTE: normal ~5-10% of diet Ox absorbed; with fat malabsobtion, 20-40% of diet Ox can be absorbed.

Mon 29 Mar 2021 Day 1 La Fitness ($20/mo, 40 per year) Fire Dr. Carl

- Litholink, no order rec’d
- Call Dr. Carl, his office calls back he wil order tomorrow.
- This GUY just can’t do it. He has enough patients; remove him. How? No point burning.

” ## Sat 03 Apr 2021 Oxalate in Food * Coe starts with Harvard, updates it https://kidney-stones.uchicago.edu/how-to-eat-a-low-oxalate-diet/ * Careful with: **serving = ?**

Thu 08 Apr 2021 I call Litholink, cancel appt with Dr. Carl

- April 2,Order was rec’d by fax
- April 5, shipped, due to arrive Monday Apr 12.

Sat 10 Apr 2021 - HERNIA Surgery

- Per Ralph Nader, applying MESH after hernia surgery is US medicine making money. Sounds simple, but high rate (number is ?) of followup pain, permanent pain, need to redo or remove.

- Old fashioned way, doing tissue repair, with NO mesh, takes longer, requires a couple of days IN hospital. Has far lower rate of failure, pain etc.
- Nader spoke very highly of Canadian hospital: https://www.shouldice.com/
- Costs could be lower or same as US mesh procedure (because it is Canada). Results will be better. Ran Paul who claims to despise Canadian health care had hernia procedure done here! https://www.cbsnews.com/news/rand-paul-to-have-surgery-in-canada-due-to-injuries-sustained-during-assault/ https://www.meshmedicaldevicenewsdesk.com/articles/rand-paul-chooses-shouldice-clinic-for-hernia-repair
- Do NOT TRUST US doctors who CLAIM to do tissue repair - it is LOST ART. Go to the place that trains and maintains the expertise.

Thu 15 Apr 2021 Litholink, Fire Dr. Carl

- 3 1/2 hours at lab for courtesy blood draw.
- One objection after anohter, I forgot lab instructions, so they called Litholink: there is NO blood draw (which is why I don't have the directions.)
- No doctor order, no blood draw! Mutliple calls to advice nurse: Constance & Donna.
- Now Kaiser says (Amanda) : We do not provide tube; you bring tube. AND you can not take the blood with you!
- rather than fix the problem, dr carls people want to counter-offer! either
- redo another day or kaiser gives the tube but blood stays wth kaiser.
- i agree with later, kaiser can process the blood …. but it must be SAME tests that Litholink would run on the serum. Kaiser calls securty!
- Wes (runs the lab, or is security) comes over. He actually listens; Will talk to Julie (?) who runs LAB.
- Finally, fax comes through, OK to do the draw, serum, tube and put in Fed EX box.
- Wait 1 hour (should only be 20 min) for the vial.
- Leave 3 1/2 hours AFTER arrival.
- 15 Apr 2021

Dear Tina:

Thank you for your time today, as well as in early January.

As you know, I have become a frequent user of Litholink. As a result, I have learned some of the rough parts and unwritten rules, at least from the patient's perspective.

Today I spent 3 1/2 hours fighting with just about everyone, just for a courtesy blood draw for a 24-hour urine collection. Something is wrong; I hope we do not repeat this.

Here are few general and specific observations, which I hope will be benefit as you revise your forms and procedures:

1. Doctors are not gods.
2. Patients are not children.
3. Patients may sometimes be right.

- First, I encourage you look at your own data. Where do problems appear? Patient error? 3rd party lab error and so forth.
- For 24-hour urine, separate directions for people using 1 jug vs 2 jugs. Standardize all terminology, fonts and so forth. Put all the papers in a single, well-indexed pamphlet.
- Remove doctors who can not follow rules. You should know who these are; ditto for 3rd party labs.
- Today, from just about everyone, I heard that there was to be no blood draw because the doctor did not order it. Well, see RULE 3. Your telephone support staff needs to know this .
- We discussed having your own staff go through the test, fasting, including some procedural hiccup that forces them to sit around (hungry) for extra hour or two.

- Today, the 3rd party lab (Kaiser) told me they never provide serum/blood tube. Please put this requirement clearly into writing so there will be no need to call Security when patient exercises RULE 3. (Am I the ONLY one with this problem, again please consult your own data.)
- Should you have an orientation for new 3rd party labs??
- Release the results to patient when ready. See RULE 2.
- Make the serum draw mandatory part of the procedure, unless doctor makes specific OPT-OUT. Similarly mandate the blood tube be labeled with patient's name and DATE of draw (Unbelievable, but this does not always happen.)
- Plenty more but hope this gets you started.
- Next to examining your data, RULE #3 is the most important and your procedures need to allow for this.
- Consider removing today's doctor from your approved list.

Let me know if I can clarify any of this or review your revisions.

Wed 28 Apr 2021 Stay away from Dr. Carl = incompetent. (see emails)

Wed 28 Apr 2021 Litholink, collected: 15 APR 21 (low Ox + zenpep)

First Look:
Attached please find latest Litholink Report. Note: This is first with Pancreatic enzymes. DIET is also very low oxalate. (Diet records available.)

Results to be discussed with Dr. Lieske, Mayo Clinic, tomorrow (Thursday).

Do you have any comments?

Thur 29 Apr 2021 30' with Dr. Lieske, Mayo.

- Subset of people who do not respond well to pancreatic enzymes.
- Suspects bacteria issue as well. (misalignment, out-of-balance) But does
- not recommend antibiotics at this point. Hernia repair … will not help
- UrOx. So do it for other reasons.
- Stay with Enzymes … repeat 24-hour urine 4-6 weeks, stay low Ox diet.
- He will order Mayo 24-test (uses preservative) So no more Litholink!
- I complained about low Ox diet and UrOx 71 is WRONG direction.
- He seems to feel UrOx unchanged, but I emphasized lower Ox diet AND Zenprep should have been lower.
- Candidate for trials: 2 year study.
- Feels certain I have ENTERIC HYPEROXALURIA, due to fat malabsorption/pancreatic atrophy.
- Seems he can tolerate 70 (really !?), just stay away from huge prior numbers. Not sure I understand what he is saying here. Said I will probably never be able to get UrOx into normal.

Sun 16 May 2021

Dear Dr Wong: Just update:

- now about 8 weeks on pancreatic enzymes.
- same subjective comments as before: seems less bloating, better stool.
- April litholink - showed no effect on UrOx (even with better diet ??)
- June - will speak with Dr. Lieske (Mayo); believe he wants another 24-hour urine.

- fyi, small weight loss! maybe 3-4 pounds and continuing to fall. Weight now: 146 1/2. Adult life always > 150, **EXCEPT with vigorous exercise** (indoor rowing); diet and gym insufficient to reduce weight.
- per Dr. Lieke renewed effort to be on low-oxalate diet. In practice, however, this means more **JUNK** ice cream, bread, sugar has replaced dense,nutritious foods like beans, soy, nuts, boiled high fiber, whole grains kernels, one pound of leafy vegetables per day.
- not eager, but if you need evidence that enzymes actually doing anything, very willing to any of these; Colonoscopy, kidney x-ray, Sitz test. As you know, first two have had difficulty.
- fully vaccinated

F 28 May 2021 call Dr. Bilbao, reduce medications?

- Suspects I do need thyroid
- Trial: remove for 30=60 days; retest between July 1 and Aug 1
- Then, separately, remove Welbutrin
- Finally, separately, Efexsor
- Not sure I understand her order, but ….

Sat 05 Jun 2021 3rd 72-hour fecal Stool (5/24?/21) Fat is 20 g/24 hr (normal <7g /24 hr)

- Down >50% from 4/2/19 (44 g/24 hr)
- And …. 10/31/18 (34 g/24 hr - I didn’t eat enough fat?) ## Tue 08 Jun 2021 Thyroid medication
- Feel a little run down; lack of sleep or is Thyroid kicking in?

Sat 26 Jun 2021 dr. bilbao - changes to medication:

Dr. Bilbao:

Appreciate if you advise me on the following, mostly OTC:

1. **Asprin** - 81 mg (~ 21 years)

   Have read the benefit accrues over time; by early 60s additional benefit is minimal.
   Proposal: Stop?

2. **Psyllium Husk** (~23 years)

   Of all the UrOx, GI, pancreas interventions, only this one observe the benefit.
   Proposed: Continue.

3. **B vitamin complex**:

   B12 (5-6 years) - Prior doctor suggested, per age and diet (mostly vegetable at that time). Diet now rich in dairy (2-3 servings per day); chicken (once per week); includes eggs.
   B6 (4 years). - At my request, per mention in literature suggesting B6 reduces UrOx even in NON-GENETIC UrOx. I saw no benefit.
   Proposed: Stop unless reason.

4. **Vitamin D3** - 5000IU x 3 per week; (~7-8 years)

   Blood test showed deficiency (18). Since then range from high 20s to 40 or so. Besides supplements, also increased sun exposure (5-10 min per day; in summer).
   (prior) Higher dose 5000 IU x 5 per week: no effect on parathyroid.
   Proposed: Continue? Brand recommendations?

OTC are unregulated, with poor track record. Contents include ingredients I would never willingly take. If necessary can continue but appreciate any guidance re: brand/specific ingredients.

5. **Levothyroxine** - 100 microg.
   Please recall June 1 stopped. Blood test: early July

Mon 28 Jun 2021

Dr. Bilbao says:

“Ok to stop the aspirin, B12 and B6. (no benefit for aspirin for primary prevention, and sounds like you are supplementing in diet for the Bs) Take 400-1000 units of vitamin D3 on days when you do not receive 20 minutes of direct sunlight. Ok to continue psyllium husk.”

- D3 seems too low; will cease D3 till fall; then do as she says; ask to retest D3 in Dec?

Thu 15 Jul 2021 Dr. Lieske - no results 24-hour urine.

Waste of time. He has no results (Collection ended 18 JUN 2021). Says may need to redo. Asked for written prescribed diet (as in clinic trials): he just repeated low OX. I said I think I’ve been doing this, but I am human. Wouldn’t it be better to revmoe one variable? Trials? Again I said yes, if in exchange for my body, I get a through exam/history b/c no one who has seen me has experience. Re: GFR what is important is TREND, not actual value. Any questions I should ask pancreas doctor re: fat malabsorption, UrOX. He couldn’t think of any. I mentioned high PTH, even with D3 - he made no comment.

Not useful phone call.

Thu 22 Jul 2021 Dr. Sadana:

1. First, I apologize for phone visit (July 22); my phone just did not ring.
2. Two key `facts`:
   - Given MRI, stool fat and no lab errors, I do not doubt **pancreatic atrophy**. No recollection of chronic pancreastis. No symptoms of fat malabsorption [2]
   - Also very clear I have **hyperoxaluria** (high UrOx), whose value varies widely. However, pancreatic enzymes do not appear to have any affect on UrOx [3]
3. Two key questions (not necessarily for immediate answer).
   - How would you describe the **health** of pancreas? What should I be doing to maintain pancreatic health?
   - The bottom line: What is the medical benefit of continuing to take pancreatic enzymes?

Tue 27 Jul 2021 Dr Bilbao now wants to 'coordinate' see EMAILS

Tue 27 Jul 2021 Suntan, UV: mineral, SPF>30

- UVA ages skin
- UVB can burn skin
- SPF is silent on UVA; Therefore want (1) SPF >= 30-50 for UVB and (2) 'broad spectrum' to pretect on UVA; SPF number means reduces by factor of 1/SPF
- SPF =50 is money waste.
- TWO types of suntan lotions:
  - (mineral) best for sensitive; zinc oxide/titanium oxide; works by reflecting light.
  - (organic) absorbs; therefore can become hot
  - SPF =50 is money waste.
  - TWO types of suntan lotions:
    * (mineral) best for sensitive; zinc oxide/titanium oxide; works by reflecting light.
    * (organic) absorbs; therefore can become hot.
  - TIPS:
    * Easy to miss spots; must really lather it on. Not place to be frugal.
    * Every 2 hours;
    * GLASS: UVA passes.
    * WATER (pool): yes, sun can burn.
    * CLOUDS/TREES: UV passes.
    * LIPS: SPF >30.
    * Creams: BEST for face.
    * Lotion: Less grease.
    * GEL: hairy places; scalp, chest
    * 2021: $9 for mineral version of suntan protection. CAREFUL: may stain!
    *

[2] No malnutrition, anemia, diarrhea.
[3] Evaluating this with Dr. Lieske (Mayo Clinic)

Mon 02 Aug 2021

- Phone w/ Dr. Bilbao: she requested this appt, blocked Litholink order until this. Also blocked changes to brain meds until appt. Her call is 10' late.

- Today, sjfd;sonly discuss litholink order, Dr. Lieske. No discusion of psychiatric meds. Out of time.

- Today: does not read email. So spend time finding July 2, 2021 med update I sent. Then no review of it.
- Dr. Carl: seems very interested in why not working with him; repeats a few times, until I said 'not qualified' or most doctors see ONE case like this in a lifetime.
- Then I need to review whole history with Dr. Lieske and pancreatic enzymes. She has no medical info, appears to be using the time only to get up to speed. Again repeats, more than once, that emails are at her own time and best way to communicate is: voice.

- No mention that we did TRY to do this; she had dropped the ball. Guess burden is on patient to track down doctor.
- More than once says she really wants to help. Wants to go beyond … really? News to me … you've been out of picture, now you re-insert yourself.
- So we finally get to Litholink…. Takes awhile to (AGAIN) explain how Litholink wants it done: patient does legwork, after doctor signs. Here is where trouble begins. At least 2 points, I said I don't know what doctor sees: please call Litholink.
- Can't send signed copy electronically; does not want to send signature on blank piece of paper (isn't it a form)? So she insists she will fill it out/fax to them. (No mention about long prior delays; does say she'll do it Tuesday when she's back at office.)
- Next I raise 10-day hold on Litholink results. Insists that way she will do it is: wait for paper copy of results (will not go on online and release it), Then she (or assistant) takes picture (?) and uploads to their system. Patient can not see this uploaded file, so she (or assistant) can then MAIL me the photo or whatever it is. Can not do it electronically. Explained I need this to give to outside doctor.
- Team: at some point, I objected this word. I don't see any team.
- She seems to like to summarize things by ADDING in things that I did not agree to. So I have to unwind it, example: I don't know why this or why that … and try to push burden on her to, for example, call Litholink for any details.
- Seems to present this is as `choice`. I reply I am not your boss, but not happy with such a manual system; especially given the actual DATA there are all kinds of delays. Says she wants to do all she can to help, but is at her limit. She notes that both of us seem to betting upset. (Yeah, you claim to do all you can, but want to strictly adhere to system that introduces ADDITIONAL delays. In past, I had to call Litholink to get things to move: but I did not say this.)
- Now I am pissed. She repeats no time for emails. Think she said she will review Lieske' notes or whatever, but I am not convinced … She rather proceed by telephone call (with me).
- ZERO discussion of Wellbutrin.
- I get off phone and call Kaiser to change doctors. Denise Bilbao has not proven herself very effective at anything, except delaying. Out of time.

Fri 20 Aug 2021 Litholink arrives Wed 18 AUG 2021 (Dr B said she'd order on

3 AUG; 2 week turnaround); Mayo clinic fucks up 24-hour urine kit AGAIN. * Fed up with doctors. * Mayo clinic appears to be highly overrated. * What is point of 1 more 24-hour urine.... I don't think they know.
Mon 20 Sep 2021 * Anti-inflammatory foods. Handout from Dr. Montonaga similar to this: https://www.verywellhealth.com/anti-inflammatory-diet-88752. Usual advice (plants, good fats). (much conflicts with low-oxalate) * slow-cook beans, makes more digestible; also `sour` like pickled raw vegetables easier to digest (carbs break down) * kombu, mineral rich sea veg, increases digestion in beans, grains. Wikipedia says seaweed including kombu rich in enzymes that break down all kinds of otherwise hard to digest foods. (even 1 piece in beans, or stew)

Wed 06 Oct 2021

- BP today (by nurse): 139/93 yikes! Then 137/73 ?

- Get to GYM !
- Primary care doctor; change to Dr. Jan..... in Eugene
- flu injection today.
- Anti - pneumonia injection today.
- By 9-10 pm; feeling sick; slight aches, fever?, slight head aches ....
-

Mon 18 Oct 2021 call from Dr. Kaiser - GI _Pancreas)

- Repeat MRI w/contrast
- Can increase dose (titration) to 36,000 (to see if UrOx decreases).
- Claim: 20-30+ cysts is more than usual; but it is size that matters; above 3 cm is concern; my largest is 2.1 cm. So just need to watch. 15-20% of population have cysts.
- Claim: purpose of Zenpep, enzymes is to PREVENT **protein catabolism malnutrition**; ie it is protective. (do I have this right? I think he means protective against malnuitrition; not protective of pancreas. No malnuitrtion now, but could become worse? Reason?)
- Most of his patients have reach protein catabolism malnutrition: few options to treat; weight loss; as body breaks itself down for nutrients. (Told him: no indication of malnutrition). Easier to dose enzymes because can see effect on weight.
- He acknowledges I am 'atypical'.
- In this sense, I caught this early ... At present, he did not seem to indicate any danger: just monitor.
- UrOx, kidneys ... not his area of expertise. Does not know (or think) relation between enzymes and UrOx. Gave him Lieske's name. Recent TEST summary: ## Sun 24 Oct 2021
- Eye coverage: checked with Kaiser, I do NOT have any eye coverage, no glases, no exam. (gheez, Medicaid was *better!) ## Sun 24 Oct 2021 Humana - telephone > 1hour on phone; website sucks; (couldn't get `Suite 407D` in address; today I see post office returned to sender (1st ordered ~OCt 6) for Zenpep. Steve (on phone) excellent: knew what to do and did it; though took HIM several internal calls,holds .... Zenpep ... even they can't fill right away ... will be out of medicine (Zenpep=30 day supply). **WARNING**: excpect problems with Humana. ## Mon 08 Nov 2021 1 week w/o Zenpep Zenpep arrived today; So 1 week without Zenpep; Very few changes noted during week; perhaps a bit more gas; and if anything stool a bit firmer, daily. No other changes apparent to me. Now returned to full daily Zenpep dose.

Thu 18 Nov 2021 Zenpep -

Zenpep - a bit over 1 week since rec’d mediciene and resumed. Stool has returned to prior pebbles (large); reversal of what was beging with without the medicine (larger). Not aware of any other changes now I that I am BACK on the Zenpep.

Thu 18 Nov 2021 Dr. J.

Couple of attempts for her to reach me. First, my fault - just forgot!. Secnond time, phone says joing video conference… and did not like my browser (wnats Chrome, which had to install). Pain in butt.

Sat 20 Nov 2021 response to Dr. Mummadi:

I agree the patient should ultimately decide, but the patient should also be `informed`. I do not feel informed.

So I rely on your knowledge and experience, as well as judgment, to clarify the pro and con of each decision.

Appreciate if you look over the following. You will have a better idea of what I do and do not understand.

Fecal Fat per fecal weight: Could you comment on the attachment I sent last week? Do you agree there little efffect with Zenpep? Am I correct to divide by fecal weight?

How should the graph appear in a typical case?

Protective During our October 24th conversation, I believe you said enzymes would be **protective**. In particular, you said **protein catabolic malnuitrion**

Since I don't think I have malnutrition now, I do not understand your meaning or whether you are refering to the pancreas organ itself.

This chart summarizes what I think . Am I correct? (items in each row are unrelated)

I do have	I do NOT have	Not sure?
PEI	Diarrhea	How will this progress?
cysts <3 cm	Steatorrhea	no reason to suspect H steatocrit
> 20-30 cysts	Malnuitrition	Bacteria overgrown?
pancreatic atrophy	blood markers	Complete stool analysis?
	Chronic Pancreatitis	
	Pancreatis (inflammation)	Breath tests? 13C, glucose?
gallstones (factor?)	blockage of enzymes	Possible to have TWO factors?
	insulin or endocrine problem	
Mumps (as child)	no Celiac	
High triglyerides (< age 35)	no constipation	
enteric hyperoxaluria	no LUPUS	
lactose intolerant		

Except for age ~18 when found to be lactose intolerant, I have NO recollection of extended bouts of diarrhea. None in recent memory; even colonscopy prep produces this only with great effort.

Paper Some of information is based on this paper. Is it not recent; but I find it readable. Can you suggest something newer?

World J Gastroenterol. 2013 Nov 14; 19(42): 7258–7266. Published online 2013 Nov 14. doi: 10.3748/wjg.v19.i42.7258 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3831207/#

Comment: From the paper:

> In cases that do not respond to initial treatment, the doses can be doubled, and proton inhibitors can be added to the treatment.

Do you agree?

> Pancreatic exocrine insufficiency (PEI) can be defined as a reduction in pancreatic enzyme activity in the intestinal lumen to a level that is below the threshold required to maintain normal digestion. This concept is crucial ….

Debate

Of course, I would like to know both sides of this.

> The need for PERT in PEI without symptoms is a matter of debate, and randomized clinical trials on this issue are lacking.
>
> Nevertheless, certain collateral evidence supports PERT, even in the absence of overt steatorrhea and weight loss: (1) A longitudinal study in patients with CP demonstrated that patients with no clinical symptoms of steatorrhea but an abnormal steatocrit who did not receive PERT lost more weight than not only CP patients with a normal steatocrit but also patients with an abnormal steatocrit and symptoms of steatorrhea who were treated with PERT[63]; (2) Laboratory signs of malnutrition have been demonstrated in a large proportion of patients with CP and asymptomatic steatorrhea who were not under treatment with PERT[64].

Do you agree blood tests can indicate malnutitrion prior to other symptoms appearing?

> It is reasonable to assume that such malnutrition-related complications will be preceded by deficiencies of macro- or micronutrients detectable by routine blood tests…
>
> …The central conclusion that can be drawn from this study [see paper] is that a normal panel of serum nutritional markers can exclude PEI with a high negative predictive value.

This theory has been floating for post 2-3 years. Your analysis?

> If PERT is ineffective despite an increased dose and adjuvant treatment with PPI, the diagnosis of PEI should be revised, and possible coexisting and/or alternative reasons for maldigestion, such as small intestinal bacterial overgrowth, should be considered.

Thank you

Sat 27 Nov 2021 Dr. Lieske (2nd litholink + u/s: stone!)

Dear Dr. Lieske:

Happy Thanksgiving.

Attached please find 3 items.

1. 22 OCT 2021 - 24 hour urine w/ enzymes (UrOx: 85, Litholink)
2. 11 NOV 2021 - U/S (13 mm stone!)
3. Fecal fat vs Fecal Weight (3 72-hour stool tests)

Please recall our conversation ~ 29 APRIL 2021. We agree to verify 15 APRIL 2021 Litholink. That 24-hour urine report, the first WITH Zenpep enzymes, showed slight UrOx increase vs prior non-enzyme report.

Note the recent U/S which shows NEW stone that did not exist in prior U/S (DEC 2020)

And finally my graph comparing fecal fat to total fecal weight in 3 72-hour fecal fat tests. The third is WITH Zenpep.

Taken together I can not observe any measurable benefit of Zenpep enzymes.

Your thoughts?

jim rothstein

Wed 20 Dec 2021 Humana: Transfer Rx: Request #OCP010300924804

Don't know what's up with Humana ... Refill (Tamoslosin) for ordered 12/12 apparently did NOT go through. Call on Saturday Dec 16 and so ordered again. Today, 20DEC I don't see any order. Also transfer all 11 prescriptions from F Meyer, but I've done this before also. Transfer Rx: Request #OCP010300924804 for all 11. Later same day ... Fred Meyer has filled 30-day supply per Dr.Lam - 45' wait (line!) + travel .... b/c Humana sucks.

Humana is **PDP** provider (for standalone part D, not Mediare Advantge), per Medicare. There are 766 of these; 23 licensed in Oregon. All seem to be private; several with rewiews WORSE than Humana.

Thu 20 Jan 2022

In Eugene, Kaiser uses Valley River (?), but no phone for them. They will call me when opening. So I made appointment in Salem at KP.

Sat 29 Jan 2022 Dr. Lam urology | CT Scan | Summary of phone call.

Tiny stone (means < 1 mm). But ultrasound thought 15mm ?? Later he acknowledtes next time try KUB 1st. My error: CT Scan is NO contrast. (MRI had) Using CT + contrast blocks out the stones. Prostate size - nothing to do "normal" - unless some urinary problem. Vascular calcification - yes plague, by age 65 western diet = some atheroscleoius (but I most vegetarian ?). No aneuyysm means NO buldge in vessel that may break. He concludes that despite high urinary OX, I am doing good with preventing stones. Told him in the K Cit; and thought UrOx is bad on itself.

Wed 1 MARCH 2022 - nutritionist

Kaiser nutritionist telephone appt - said "1 time education" ; said I've been through this; agreed that she would ask Kaiser kidney dietitian for input.

Fri 25 Mar 2022 - 2nd CT reading, bladder now has prtrusion; 2 small stones

GAP lost files!

May 2, 2022

Litholink: urine leaks, only blood result

May 11, 2022

Repeat Litholink: blood + urine Stunned: Urox=45 w/ Ca, ZenPep, KCit; but I was not low-Ox (ate lentils for instance)

Sun Jun 5 00:14:05 PDT 2022

Call with Dr. S - Friday. - **Zenpep**, agrees does not appear to be benefit. Stop and repeat 24-hour urine in 60 days (August). Lengthy discussion re: CT scans vs ultrasound and what to do going forward. I have no answer.. just continue. - **Effexor** reduce dose by 1/2 for 30days. Monitor and report to her any changes. If no changes, probaby ok to go to ZERO after 30 days. But report to her. - Make appt for July 18th or so. - **Wellbutrin** no change. She was a little suprised I was put on Effexor first and that it had positive effect. (she dislikes drug; except great for hot flashes) - Litholink: repeat 60 days (August)

Stool notes: +1 day (1/2 dose of Zenpep.) Some extra gas; but bowl movement is regular.

Wed Jun 8 10:58:20 PDT 2022

8 JUN 2022

Dear Dr. Jhansale:

Just a followup to our conversation last Friday (3 JUNE).

We agreed to do the following:

ZENPEP

Appears to be little evidence of improved UrOx with Zenpep, continued use of medicine does not seem warranted. As a test, I will taper Zenpep to zero pills per day. In mid-August (~60 days), I will repeat 24-hour urine (Litholink) and review with you.

- The official textbook treatment of pancreatic atrophy, which I have, are use of these type of enzymes. Indeed there **was a reduction in fecal fatty acid**. The issue is that no other benefit was observed. The usual symptoms (diarhea) never applied. One doctor(GI, left Kaiser) said to follow the science (textbook), another (Pancreas, left Kaiser) said my "body may have adjusted" to lack of enzymes. Two others (Litholink and Mayo) observed that sometimes symptoms (diarhea) do not appear and (Mayo) in some people (a few, a couple ?) enzymes do not reduce UrOx.

- Separately, I will update chart of all my UrOx numbers (since 2014) and send copy to you.

- The long term health effect having little to no pancreatic enzymes is UNKNOWN to me.
- The long term effects, however, of UrOx is **NOT benign** (medical literature). No doctor been able to provide clarity or effect prevention.

Effexor

Will begin 1/2 dose (~ 1 week when I get the medicine) for 30 days (to mid July). Will report any significant changes immediately to you. If all goes well, will be using only Wellbutrin going foward, till we review. - Am aware your experience with Effexor for mental health has been not been as successful. However, I feel I must report that beginning with Effexor, followed soon after by Wellbutrin, in 2014 ended all reported symptoms. I have been very stable since and feel I am fully functional, albeit still unemployed.

- Said another way should I miss the Effexor, I would have no objection to resuming.

Litholink

- Suggestion: Would it be easier if I prepared the Litholink form and then send it to you electonically? (in late July)
- If yes, appreciate if you then (1) sign it (2) fax it Litholink (number on form) and (3) be sure to prepare "Courtesy Blood Draw" request for Kaiser Lab. Eugene lab is not strict on this, but Portland/Salem are extremely strict - no form, no work, no negotiation (they have called Security on me).
- Second Suggestion: Given the persistent HIGH UrOx numbers, I hope you would be willing to speak directly to Litholink's medical head. Litholink sits atop a vast treasure of urine and kidney stone data. I spoke with this person, but I feel you, a doctor, might make more progress. (If yes, I will need to prepare you with questions). This is not an immediate need.
- Please recall that last litholink (2 May 2022) leaked urine, but the lab did do the blood work. We have the report.
- I think did a SECOND 24-hour urine (blood+urine) and sent this to Litholink. There is still no report.

Thank you.

Jim

Fri Jun 17 19:35:47 PDT 2022

- Zenpep, since June 5 tappered from 11 per day; to now 2 per day. All seems fine; stool now returned to elongated, swollen banana shape. Feels good!
- First week or so, at 5 or 6 per day, stomach got a little angry: gas, slight discomfort; no diarerha. Still regularly; daily. After week or so, stomach calmed down. Now everything seems very good shape.
- But UrOx, stones, fat in stool – no idea.

Tue Jun 21 14:34:37 PDT 2022

- Zenpep gone now for 4-5 days? (let's say JUN 18=zero) Just mention it: seem to have started to SCRATCH myself! everywhere: arms, legs, neck, stomach …. no sign of skin issue.
- Stool not elongated or swollen, ie misc chunks. Zero sign of loose stool.

Thu Jun 23 23:25:52 PDT 2022

24 Jun 2022

Dr Jhansale:

Update: VENLAFAXINE 37.5, Zenpep, Litholink

0. June 18, 2022 (Zenpep): Last day of use (now zero) (Stool normal, regular, no sign of digestive issues at all)
1. June 24, 2022 (VENLAFAXINE): First day on 1/2 dose (37.5 mg)
2. July 22 (Next telephone appt:) review VENLAFAXINE
3. August 21 (Next Litholink) evaluate 60 days without Zenpep (I will provide you with paperwork, early July)

Additional Notes: **Itching** With 2-3 days of zero Zenpep itching began on all 4 limbs, abdomen, thighs, neck, groin & shoulders. No signs of skin rashes. But can't seem to stop.

Exercise Joined local Y. First real exercise in 800+ days (aside from pushups, jumping jacks, daily 10000 steps). Main exercise is indoor rowing machine (poor man's MRI + exercise) b/c of deep breathing. Past benefits rowing return, including mental health.

Litholink - new result: Urox 45 Litholink results (May 11, 2022) - I just rec'd these results. Full Zenpep, Calcium, KCitrate etc. UrOx = 45, no special diet (ie NOT low-oxalate) stunned. Did Zenpep have effect or not? Will review with you July 22.

VENLAFAXINE & Insurance For years, insurance paid. Refused to pay for 1/2 dose (37.5 mg)! "not in formulary" (I paid $26.15+ for 30 pills). Ins company now faxing you forms they need to approve.

Thank you. Looking forward to more rowing.

Sun Jun 26 18:50:56 PDT 2022

Itching - Drew blood today (shoulder) - 1 week; began a few days AFTER last dose of ZENPEP. - Began BEFORE reduced Venfalaxone (37.5); BEFORE joining Y; - trimmed nails; wet cloth on wrist (instead of scratching) - thighs, groin, arms, legs; not backh - No shirt, seems to help, actually. - No sign of rash or yellow or skin issue - With movement: no itching problem.
- Sleeping: no itching problem: - **Sitting or Stationary: This is problem.** - https://blog.dana-farber.org/insight/2020/02/is-itching-a-sign-of-pancreatic-cancer/

Wed Jun 29 12:08:15 PDT 2022

Resumed Zenpep today. - No change in itching to date. - Today, discussed with doctor on call (?) or via the nurse? - They made appt for me: next week.

On theory that loss of Zenpep caused problem, goal is to see if problem goes away WITH RESUMPTION. If not, stop again, seems to be no harm.

- longer walk; some gas; stomach seems to be transitioned (as I recall from before);
- As soon as sit down, massive scratching …
- Turn up a/c … to type these messages.

Thu Jun 30 14:35:45 PDT 2022

- DOSE today: efforex 1/2 dose.
- ZENPEP full (11 tablets) dose.

  -'Itching started 3 days BEFORE change in efforex.
-
- Misc Notes:
- poor sleep; (itching)
- To sleep or stop itching: a/c - very cold, sleep under desk.
- itching resumes as soon as awake.
- Getting worse? don't think so, but tolerance/patience has sharply decreased.
- Unable to most common tasks: cook, type, work … just want to lie down; Not because tired; but sleep is only way to get relief from itching.
- So many 2nd affects; eating poorly, trouble hydrating … just rather lie down, doze. No desire to do any work. Not like depression; just losing battle with the itching. Tired of splashing water; rubbing in Hydrocortizone.
- Today bought coffee (none yesterday - rare, very rare); will make effort to WALK to Y (did not go yesterday).
- AFTER Y, long walk, exercise, shower - ALL good, no itch. Hot sun on skin - no itch. Effect lasts couple of hours.
- Hyrdorcortizone 1% - works IF apply frequently, hourly? And must apply asap - before really scratch.
- Trim NAILS! but not so much that Nails hurt. Tricky.

Fri Jul 1 20:24:50 PDT 2022

- DOSE today:
  - efforx 1/2 dose.
  - Zenpep full dose (11 tablets)
- AM stomach seemed ok, but by afternoon BLOATED, gas, gained 1 pound ! (149 to 150), sulfur taste; begins to lessen by midnight.
- BLOOD TEST today (A1C, metabolic)
  - GLUCOSE: 134 !! (not fasting, but LONG walk to get to clinic; breakfast was oatmeal, yogurt, orange?, one piece of whole wheat, banana, apple.) Remember getting to Clinic a bit tired and had to sit down; not normal for me.

  - A1C 5.6% Been rowing every day almost everyday past week.
  - Other numbers all seem fine, Bilirubin well within normal.

- ITCHING

  - walking, shower, rowing - no problem
  - begins when stay still.
  - new a/c in office; trying to keep room COLD to suppress itch.

- Stomach

  - bad egg taste; feel very bloated.
  - I assume related to re-adjusting to ZENPEP (siimlar to before)
  - not exactly normal, but these are minor effects. ITCH is #1.

Wed Jul 6 04:11:09 PDT 2022 visit Dr.

- Suspects NOT realated to Zenpep (or efforex or …)
- He is not certain: might be SCABIES, which has `simple` treatment.
- Treat ONE night; but still takes several days or more for ITCH to die down (Itch is body's response to this mite & its determinents)
- ALSO, says VERY DRY SKIN, recommends OTC lotions for dry skin. (I buy Avenno something.)
- To reduce ITCH sensation, recommends ANTI-HISTOMINE. However, I see warnings about kidneys - is this one of no-no medicines? So I do not buy;
- Stay with Hydrocordizone 1%.
- IF CONDITION CONTINUES … then will send me to DERMITOLOGY for possile STERIOD use. Does NOT want to use STERIOD till clearer picture. Makes sense to me.
- With a/c | with aggressive Hydrocordizone - before deep ITCH | and sprinkle bit of water | exercise; I think I can manage.

SCABIES - Die after 2-3 days without human skin! - Isolate clothes, towels in plastic …. or wash hot water, hot dryer. - Usually passed human-human skin contact (10 minutes or more) - Where did I get this??
- TIME to CLEAN CAR!

Thu Jul 7 21:57:15 PDT 2022 SCABIES

- REF: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6532717/
- Beginning 10:30 pm 6JUL to 12:30 7JUL (14 hours)
- MUCH IMPROVED; still itching, but less intense; easier to manage with HydroCordizone
- HOWEVER, itching DID return 8 hours later; failure to respond quickly to ITCH with hydrodrocorizone only increases itch & scratching.

- ie ACT FAST

9 JULY 2022

– NO REPLY NEEDED –

– **re: INSURANCE DENIAL & VENLAFAXINE ER HCL ER 37.5 mg TAB**

Dr. Jhansale:

– Please recall our plan to REDUCE VENLAFAXINE (from 75 mg to 37.5 and then, hopefully, to ZERO)

– Insurance company has always paid for 75 mg, but REFUSED to pay for 37.5 (non "formulary"). You ALSO sent supplemental paperwork to them.

– DENIAL (date: 7/2/22) They sent you a copy as cc.

– **IF you are too busy to deal with this, I am happy to DROP matter.** (I won't miss the $26 I paid)

– HOWEVER, based on cumulative experience this company, HUMANA, appears to have trouble with the most routine (banal) duties (wrong email/url addresses, denying requests b/c, they claim, unable to contact a Kaiser doctor). I do not know if this deliberate business strategy, or simple incompetence. In fact, BOTH 75 mg and 37.5 mg appear on their formulary!

– REGARDLESS, I wish to document their conduct, ie one data point, and later present it to those with more clout than I do. All of this just to taper, and hopefully end, one medicine.

– Again, if you are too busy, I will drop it. Otherwise, I proceed to the next rung, to request "independent" review, which requires from you (see page 4 of 9 of their July 2, 2022 DENIAL):

> "your prescribing doctor … must submit a statement with your appeal request indicating that all the drugs on any tier of our formulary (or the PA/UM requirement) would not be as effective to treat your condition as the requested drug, or would harm your health."

Thank you.

jim

Sun Jul 10 18:55:44 PDT 2022

Status Now:

Effexor: still 1/2 dose
Zenpep: still full dose (11 pills)

ITCH: Remains dominant. Can not tell if improvement or responding quicker (see below).

What I did

- 5 JUL: Saw you Tuesday 5 JUL
- 6 JUL: Medicine ready; applied head to toe: 10:30 pm for 14 hours | woke itching and reapplied small amount.
- 7 JUL: 12:30 Shower off
- DAILY: wash skin/ treat ITCH with 1% Hydrocordizone; VASALINE: scratches; used sparingly AVEENO “Daily Moisture”, “Dry_skin”; Dimethicone 1.% (expensive)
- DID NOT PURCHASE ANTI-HISTIMINE (recall processed through kidney; believe told to avoid)
- Discard old pillows; isolate clothing; vaccum daily.

What works

- **EXERCISE**
- **DIRECT SUNLIGHT on skin** (~ 20’ per day)
- All the other stuff? minimal if any.

EXAMPLE

This routine works consistently :

- midday - WALK to YMCA (~30 minutes); en route: stand fixed in sunlight 5-10’ | exercise at Y > 30 minutes | shower (not sure essential, re: itch)
- Proceed directly to library: next 3-4 hours can **focus, work, no itch, no distraction.**
- ItCH certainly returns after 4 or so hours.

Comments

- skin (esp legs, ankles, bottom side of arms, thighs) still stratched and DO itch.
- GROIN appears less inflamed.
- Learned to respond ASAP to first ITCH with soap, water, Vasaline, % Hydro.. Reduces RISK of deep itching/scratching, but that is it. Can not FOCUS.

Misc

Fred Meyers says “a couple” of prescriptions each WEEK. each WEEK?

Can not identify source of SCABIES:

- No covid | following covid guidelines | generally very isolated.
- NO KNOWN contact with anyone for 1’, 5’, 10’ or more.
- Can I get from BUS seat? library Seat? during BLOOD Test? From cashier? From coffee cup? Door knobs? I use Asian bathroom techniques: no touch. And no sex.

vim:nospell