Herbie Messages – website blog posts, a little melanoma update plus email to Christmas List

### **Great news!**

Posted on September 11, 2018

Great news – the lymph nodes are confirmed as clear as of 2018-09-11. Hallelujah! Thanks to each of you for the expressions of caring in varied ways, especially the strength and support you shared with those thoughts and prayers!

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

### **Health Update**

Posted on September 6, 2018

For those who were receiving Herbie updates, it seemed worth letting you know about a recent melanoma diagnosis. Those details, should you be interested, are HERE: http://www.stevelong.longmemories.info/herbie-medical-updates/

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

## Herbie – RIP

Posted on April 12, 2018

Today was hopefully my last day at Anderson Mercy Hospital as a patient for a long, long time. We were skillfully registered by Jillian; ushered to and cared for in "my SSU room" by Glenda and Angie; wheeled up to the CT Scan by Ronda and Ashley (without hitting the walls or other obstacles!); CT Scanned by Tracey and then cared for well over an hour in the Radiology/x-ray room by Ronda, Ashley and Dr. Charles Young (with guest appearance by Erin.)

I mention the names above to provide you a glimpse of the number of folks involved with my care each week. I've written about Mercy Anderson as a precious gem in the Anderson

Township jewelry box and it's the people more than the building structure that I reference. These people have made the hospital experience wonderful in spite of the medical nuisances. Please do me a favor and hug someone you know in the medical profession the next time you think of it. Should they ask, tell them "it's for all the Steves they deal with so effectively and lovingly."

On to the Herbie news. The third sclerose agent, <u>betadine</u>, seems to have successfully finished the task of deflating Herbie to a fraction of his original size. Most of my last several days have involved no drainage which was a priority before completing treatment. So, today we performed one last betadine sclerose and took Herbie's tailpipe out. That little 12 inch piece of pipe/hose is

a welcome removal. We now count on Herbie to stay entombed with no further awakening. Herbie RIP!!!

How can we fully thank you for your part in making this journey so successful? We can't. What we can do is share our thanks in these words plus hugs, words, smiles and other future expressions of appreciation. Here's a video expressing a little of my thanks for your love, support, thoughts, prayers, notes, cards... https://youtu.be/hVPCZe k4Ec

Many thanks for all you've done to lift me up as though on eagles' wings. While doing some reading this morning, this Krista Tippett quote resonated with me:

"The intention to walk through the world practicing love across relationships and encounters feels like a great frontier."

Thanks for navigating this great frontier with me, practicing love on me. I've felt it "big time!!!!!" I love you!!!!

Steve

Posted in Uncategorized | Leave a reply Edit

## Herbie Uncapped: is third sclerose agent the charm?

Posted on April 6, 2018

Well, Herbie was not one to be capped. Within 24 hours we were seeing evidence that capping was not a solution so last Friday afternoon we went back to the 'ol tube & bulb to release that pressure.

This morning we went in for a treatment with the third and final sclerosing agent (we kept the agent in for an hour so Herbie got a full dose.) On 4/12 we will be doing a CT Scan to see if we've reached as much "Herbie hardening" as we might ever expect. If so, that will be the day we pull out the drain and then will play the "wait and see" game — will Herbie become a mostly-hardened cyst that never causes another symptom or is likely surgery on the horizon...

Kim has been a great source of support on this journey and that continues to this day. We'll continue to be inquiring, prayerful and persistent. We are both EXTREMELY thankful for all the blessings you all have showered down upon us in so many forms: prayers, cards, calls, other acts of kindness and much, much more. Many thanks, one and all.

With love, prayers and thanksgiving,

Steve

While trying to balance my mindset in association with all that's going on with Herbie and his side-effects, this quote really caught my attention:

"The soul is not simply within the body, hidden somewhere within its recesses. The truth is rather the converse. Your body is in the soul. And the soul suffuses you completely." ~ *John O'Donohue (1956-2008), Irish poet and priest in* Anam Cara: A Book of Celtic Wisdom, 48-49.

[Should you have interest in reading some other favorite spiritual/religious quotes, amassed over a lifetime, they're <a href="HERE">HERE</a>]

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

### Capping the drain to see Herbie's reaction...

Posted on March 29, 2018

As anticipated, this morning showed no improvement. Our radiologists decided after trying two sclerosing agents it's time to see if we've hardened Herbie up enough that he won't cause any more trouble. The tailpipe (drain) is now capped.\*\*

#### Next steps?

- We hold our breath and hope that Herbie doesn't try to re-inflate. At 28 cc, he's less than 10% of his original capacity and shows no inclination to get smaller. We'll hope he doesn't try to enlarge now that fluid has nowhere to go.
- CT scan on April 12<sup>th</sup> to see if Herbie stays small or if he expands once capped. If there's no expansion, we'll take out the tailpipe and hope that he never causes problems (possibly even dissipating into my body over time?)

This decision is welcome in multiple ways:

- For the first time in over two months there is no extension tube and bulb, making clothes more comfortable and simplifying several daily activities
- There's some hope that we've collapsed Herbie enough that he'll give up
- Though we appreciate their smiling faces and personalities, it'll be nice to skip a week of visiting our acquaintances at Anderson Mercy Hospital

We won't get our hopes up TOO much, but it's nice to assess and then proceed as warranted.

Many thanks for the continuing thoughts and prayers. We hope and pray for a joyous Easter time for you and those you love!

\*\* the drain is staying in since Herbie is deep in the body and of smaller size now, making connecting another tailpipe more difficult (and likely painful?)

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

## Nuthin'

Posted on March 22, 2018

High hopes, we have, high hopes ... and then nuthin', for this week.

Looks like Herbie has had enough of the fizzy drink – no progress (same size opening as a week ago.) We're giving 'ol fizzy one more try just in case, but we're figuring that next Thursday we'll move to the final type of sclerosing agent\*\*\*. With that day being Opening Day for the Reds, maybe it can be closing time for Herbie (with the allowable few days to clear out his things?) We'll keep those <a href="https://hips.nih.google.com/hips.nih.

Thanks for the continuing kind thoughts and prayers for me, Kim, our family and the medical staff\*\* working with us. Enjoy the day, with a smile on your face [and with knowledge that I'm smiling at the blessings of this day, and every day!]

\*\* This week's staff member focus is on Dr. Charles (Charlie) Young. Dr. Young is a kind soul – gentle eyes, friendly manner, confident approach, similar hairstyle to mine...and a burly beard!

He reminds Kim and me of our good friend and former MWPC church member, Brian Hill (for those who don't know Brian, he is a kind, bright, gentle, passionate soul.) Dr. Young remains confident that Herbie can be hardened and left to disintegrate in me rather than requiring surgery. May it be so...

\*\*\* our understanding is that this sclerosing agent will be "introduced" twice daily by us using the drainage tube. Maybe my next career will involve going back to school for nurse's training? NAH!

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

#### Slow down, you move too fast...

Posted on March 16, 2018

The first line of <u>this song</u> likely gives the update away ... Simon & Garfunkle remind us that slowing down isn't always so bad. Wish Herbie didn't heed them so well (another drop of 10-20% from the previous week's size, so slow and steady continues.)

Despite that slowness, I'm "feeling groovy" (at least 99% of the time!) Next treatment is on 3/22 and one week after that I intend to be watching the Reds play some opening day baseball!

Have a great week ahead and thanks again for all the kind thoughts and prayers – they're assisting me in keeping the "groovular feeling!"

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

### **Slooowwww progress continues**

Posted on March 7, 2018

Herbie is at about 10% less capacity than a week ago. Progress is slow, a little like this <a href="https://humorous.nlo...">humorous</a> sloth clip from Zootopia. We'll just enjoy the scenery along the way, including my first 2018 trip outside the tri-state (headed north to see our parents!) Next procedure is on 3/16. In honor of March Madness maybe we'll shoot for a double-digit decline in cc's of Herbie capacity for that procedure?

Person of the week is Ali. She greets us at the registration desk just inside the front door on most mornings when we arrive for the Herbie-cide\*\* procedure. On some days she already has my paperwork printed and my "bracelet" ready to put on my wrist so we can almost do a walk-by on our way to the SSU (same-day surgical unit.) While we don't get a lot of time to talk, Ali has a smile and willingness to help. What a blessing as the "first face" – or nearly first face – for many folks registering at Anderson Mercy Hospital!

\*\* thanks to brother Andy, for the pesty-cide naming!

Posted in Uncategorized | Leave a reply Edit

#### **Herbie and the Tortoise**

Posted on February 27, 2018



HELP! I'm a hare stuck in a tortoise situation.

Just like in that fable, I'm feeling the urge to race forward to the finish line. Sclerosing is not a speedy process though. Our medical team says that slow and steady can win the race and that's our objective.

The good news? Herbie is down 10-20% versus last week's size and we've\*\*\* re-positioned the drainage bandaging with an apparent side-benefit (based on a couple hours experience) of more comfort!

The bad news? No driving to warm weather climes this year for extended time to see family and enjoy baseball spring training games. Home base (pun intended) allows too many of my necessities right now, including proximity for my weekly radiologist procedures. We'll miss the family time, for sure!

Next sclerose procedure is 3/6 at 8 AM. We'll hope the fizzy drink continues its shrinking ways on the back of a slightly faster tortoise?

Continuing thanks for all the thoughts and prayers, especially those focused on patience. This hare feels the support of those "big time!"

Sending love your way along with a link to a really good "Love Train" video <u>HERE</u> if you have a few minutes to hear good music and see some beautiful images of love...

\*\*\* Nurse Ronda in radiology has been a constant virtually from the start of the QR&D process. She is friendly and collaborative. Today we changed Herbie's tailpipe placement for better drainage. She and the team help make my 20 minute rotation "twirling" go quickly with conversation on any number of topics: Valentine's Day philosophies, Olympics, families... What a blessing to have compassionate professionals working with us!

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

### **Herbie is Showing Some Wrinkles!**

Posted on February 21, 2018

We had a very uplifting, productive session today. The usual friendliness of the staff certainly helped, coupled with Angie\*\* batting 1.000 on IV sticks (she's 4 for 4!)

The good news continued during the x-ray and injection process — Herbie has decreased substantially (probably 25-30%!) We installed a new tailpipe and while Herbie ordered alcohol "neat" (given his previous love of that,) we chose the fizzy drink again instead. Next treatment is Tuesday at 8 AM with hopes for continued shrinkage and minimal drainage.

Many thanks for the thoughts and prayers – please keep 'em coming. My energy levels are increasing and this past week I've been able to resume lots of activities including singing at the hospice in-patient unit and re-connecting with my wonderful friends and colleagues there. Such efforts re-charge me all the more!

Have a great week ahead and we'll hopefully be sharing positive news again this upcoming Tuesday....

\*\* Angie is an upbeat presence in the SSU — she's nicknamed me "clammy hands Steve." In addition to being a great "contact hitter" on the IV front, she is a wife, mom and is nearly ready to graduate with her next degree (she just completed an ethics paper and scored 95 out of 100 on it and is now readying for a 30 minute presentation.)

#### Maybe Herbie is a Beatles fan?

Posted on February 14, 2018

Seems Herbie is "enjoying" a theme of <u>The Long and Winding Road</u> just a bit too much. We're counting on the road disappearing for him at some point soon, but the horizon is not yet in sight.

Kim and I separately had great conversations with our radiologist, Dr. Young. Because of the location of Herbie in my body, it's more difficult to do surgery so that may be in our future, but ideally not. The result is that our treatment journey with Herbie somewhat resembles those car rides many of us endured as kids and/or as parents - "are we there yet?"

Herbie's drink of choice has changed — he's moved from ordering his alcohol "neat" and is now onto a fizzy drink (thankfully WITHOUT the umbrella.) Unless this fizzy drink is miraculous, we'll be putting in a new drain on 2/21 and continuing with weekly rounds of the fizzy drinks with hopes the output drops substantially and/or Herbie becomes a MUCH smaller presence at the bar.

For those who hated the car rides described above, you may wish to unsubscribe from this blog post. Experience shows that Herbie-like cysts can require many iterations of various possible Rust & Disintegrate agents (we're just now starting on #2 of 3.)

As for me, my intention is to enjoy this ride for what it is. It's not the ride I'd like to be taking but it continues to be filled with some of the nicest folks and provides important perspective. Along those lines, upcoming posts will likely include writing about a person who has touched my life that day and made it special. [Today's person is Andrew and I'll share more about that below.\*\*]

In closing, my wish and hope is that this moment for you can be filled with love ... and that the experience will continue for every minute for all of your days!

With love and appreciation for you on this Valentine's Day, from your friend and admirer, Steve <3

In talking about Valentine's Day with my radiology crew while waiting for Herbie's drink to be applied, I asked "any special activities scheduled for today?" This paraphrase of Andrew's response captures my feelings too:

why do I need a holiday to show my special person I love her? I'll intend to do it all year long without making a fuss on Valentine's Day and Sweetest Day...

Amen, brother! [And my follow-up to Andrew was: for those of us who need reminding to show all of our loved ones we care, maybe such days can be a good thing too? ]

#### Herbie is Resilient ...

Posted on February 9, 2018

Herbie may have paid extra for anti-rust protection — multiple applications of the QR&D procedure will be necessary since rust/disintegration has been minimal. Today we quadrupled the level of alcohol and then did the slow motion head-to-toe 360 rotation to fully coat the interior.

Hopes are that Valentine's Day this year will be the end of Herbie, ironic given the name of The Love Bug? We'll be making an 8 AM visit on 2/14 to see our x-ray/radiologist team. By then we'll hope that fluid drainage slows significantly.

The good news? No IV necessary for today and not likely for next week! © For a guy who is a "hard stick" this was EXTREMELY welcome news!

Have a great weekend all, and many thanks for the prayers, kind thoughts, offers and actions!

#### **Herbie...Rust in Peace?**

Posted on February 5, 2018

The QR&D procedure was fairly uneventful other than the "being Steve" IV challenges (third time was a charm!) Herbie had his first alcohol treatment and then they had Steve roll around in

a couple positions to fully coat the chassis. The tailpipe (drain) will stay in until Friday. Hopes/plans are for fluid drainage to stop almost immediately prompting effective rust and disintegration of Herbie. If so, that'll be the end of the Herbster.

If Herbie is particularly resilient then we'll need a second alcohol treatment on Friday. Maybe it'll help if I consume a little alcohol in the next few days? I say..."whatever it takes!"

My pain is fairly minimal now and mostly related to the drain (at least until the alcohol coating has a little time to impact things.) I'll still be taking it fairly easy for a few days but hopes are to get a little closer to normalcy.

Many thanks for all the prayers, thoughts and actions that you are sharing with me, the family and the medical community. They continue to lift us up, helping make this situation so much brighter.

More news on Friday Here	e's hoping you have	a wonderful week ahead!
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\*\*\*\*\*\*\*\*\*\*\*\*\*\*

For those who like comics, these few had me stifling laughter while waiting to go up for the QR&D procedure:

- Baby Blues boring to be a grownup http://babyblues.com/comics/february-5-2018/
- WUMO contracting to build Rome http://wumo.com/wumo/2018/02/01
- Dilbert business intelligence? http://dilbert.com/strip/2018-02-05

# February Fool's Day... Herbie QR&D postponed to Monday

Posted on February 1, 2018

We've heard of April Fool's Day and now are adopting February Fool's Day; the procedure planned for today is postponed. The drain wasn't turned on (how did Herbie make THAT happen?) The excessive drainage complicated the procedure's effectiveness so postponement was the prudent solution. We had a nice chat with Dr. Aukermann about Herbie so that was a nice by-product of the postponement, in addition to having two fine nurses with Angie and Sherry back there in the SSU with us.

Thanks for all the thoughts, prayers and actions that you shared this morning. We'll "bank 'em" for next week – we're now set for Herbie's Quick Rust & Disintegrate for Monday, February 5 at 8 AM.

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

## Herbie's "Quick Rust & Disintegration" procedure scheduled...

Posted on January 31, 2018

Steve & Herbie are now scheduled for the "Quick Rust & Disintegration" procedure on Thursday, February 1 at 8 AM. Thoughts and prayers of strength and support for us and the medical team working with us are much appreciated.

Also, we say "many thanks" for the thoughts, prayers, offers, notes and more that have been shared for/with our family. A 3-minute Youtube video Steve recorded this morning is <a href="https://youtu.be/Iz10YUvNP0"><u>HERE</u></a> (<a href="https://youtu.be/Iz10YUvNP0">https://youtu.be/Iz10YUvNP0</a>) in case you're interested in a little perspective and a whole lot of gratitude!

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

### Herbie – what a lush!

Posted on January 24, 2018

Over the course of a mere two weeks Herbie had totally refueled – what a lush! About 430 ml drained today.

Dr. Young, the radiologist doing the procedure came by early on to chat. Turns out that Herbie's consumption levels will require a multi-stage solution since injecting too much alcohol into that size cavity could cause poisoning. We'd like to avoid that.

I'm now wearing a very fashionable drain right at the beltline. We will be monitoring the fluids and about a week from now will begin the official "Quick Rust & Disintegrate" plan.

My left hip area is very sore after this procedure, but pain levels are tolerable and will be treated with regular Tylenol. Kim's taking great care of me and the far-reaching support team has been tremendous – thanks to all of you who have phoned, written notes, texted, emailed, etc.!

More to follow about a week from now. More details below on the process for those who have interest.

Many thanks to each of you. It's a Wonderful Life and you're many of the reasons why... Thanks for all the kind notes over the past several weeks. I'll hope to reply to them at some stage but right now the priority is for some R&R.

More to follow next week...

#### MORE DETAILS

Here's my non-medical understanding of the next steps in the process:

- we will monitor the drain, keeping track of volume, color, etc.
- around a week from now we'll go back in for Phase II b
  - o run contrast through Herbie to make sure he's not sharing fluids with any area of my body we wouldn't want alcohol going
  - o take those fluids out and determine the amount of alcohol to apply
  - o put alcohol through the drain to help sclerose the area (Quick Rust harden really)
  - o repeat the rusting as need be so disintegration can occur

Posted in <u>Uncategorized</u> | <u>Leave a reply Edit</u>

#### **Herbie Returns...**

Posted on January 23, 2018

The last day or so Herbie was making it clear that re-fueling was his plan. This morning's CT Scan confirmed those suspicions.

Wednesday morning at 8 I go in for a similar "biopsy-like" procedure to that done on 1/8. The difference is that this time instead of just draining him, the medical professionals will be injecting him with "Quick Rust and Disintegration" [my term, NOT theirs! © ]

My guess is that the days through this Friday will then involve plenty of R&R (but we anticipate no changes to the weekend fun already planned!)

To keep health updates at the right level for you and a little simpler for me, I've decided to use technology as a helper

- if in your prayers you're curious about updates moving forward, they'll be <u>HERE</u> (or you can do an internet search for "Steve Long Memories Cincinnati" if you lose the link)
- you can sign up for periodic email updates HERE

Hopefully Herbie's response to "Quick Rust and Disintegration" will be so effective we'll only use this health update approach a time or two!

We're doing very well because of support from Kim, "the kids," family and friends. You all are so uplifting and amazing (I've recently written an article as an outcome of some experiences thus far and it's <u>HERE</u> if you're interested.)

The best thing you can do for us is keep up the positive thoughts and prayers for me, the	e family
and the medical professionals working with us. Those prayers help in many ways! May	the peace
that passeth all understanding be with us all	

Steve

#### HERBIE BACKGROUND

An unwelcome guest announced his arrival over the holidays. We've named him Herbie and he's a mass living in my abdomen and causing some discomfort but almost no physical pain. On January 8, Herbie was drained of around 500 cc of lymphatic fluid and the labs show no malignancies in there. We were hoping that Herbie would not try to re-fuel (though we now know his intentions are for more fuel.)

Kim has been so supportive and loving during this journey. Likewise, Cliff, Ginny, Sam and other family have been there with prayers and love.

My mind-set today while dealing with Herbie:

• this medical journey is far from over but I have a loving, caring partner in Kim; wonderful family surrounding us; caring and supportive friends; a filled Binder of a Lifetime (easing my mind;) an excellent medical staff\*\* and a faith in God that remains stronger than ever!

At this point I'm still not sharing too broadly but not trying to keep it a secret either. We'll continue to welcome prayers of strength and support as the journey continues....

Steve
** We're blessed to have oncologist and good friend, Dr. Peter Ruehlman, working with us on this. He and his colleagues are hopeful but no guarantees. Herbie is still a little hard to get to know
**********************
This announcement went out to Christmas letter list on 1/28/2018
Forwarded Message
Subject: Herbie and the Boal

**Date:** Sun, 28 Jan 2018 12:15:49 -0500

From: Steve Long <stevelongmemories@gmail.com>

Wow, who knew what lengths I would go to in emphasizing the value of doing the Binder of a Lifetime (BoaL) !?!?

Turns out I'm dealing with a pretty substantial health issue, though all indications are that Herbie (the name we've given the liquid-filled cyst) is benign and something that can be treated. I won't complain about my body too much since I've enjoyed well over a half century with nearly perfect health!

So this note has several objectives:

- Inform you of my illness.\*\* Should you be interested in more details they're <u>HERE</u> (stevelong.longmemories.info) And if you want periodic updates via email you can sign up <u>HERE</u>
- Express the gratitude I feel in living life and getting to know good people like you!
- Encourage you to "start filling your BoaL now!" When preparing for surgical possibilities, it made a HUGE difference to know that the BoaL's <u>KEY INFO section</u> was completed and that Kim already knew most of life's basics that usually are my responsibility in our union! [details on this section <u>HERE</u>, including fairly complete materials you can download/print and start filling in]

In closing, let me say that <u>it's my intention to live a long life with many more memories to include in my Boal</u>. However, it's experiences like mine with Herbie that remind us of the gratitude we should have and the precious little time we have to gladden the hearts of those who travel with us. **Thanks for making my life better!** 

With love,

Steve

\*\* Family and friends have showered us with blessings of offers for support so all needs are covered. On the other hand, thoughts and/of prayers of strength & support are much-appreciated!