
Tales From the Trenches: Survivor Stories

Last Updated Wednesday, 10 November 2010

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Rare tumors

Metastatic

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The ongoing nature of the battle with bladder cancer has led some survivors as well as caregivers to refer to themselves as warriors. Many thanks to the people here who have generously shared their experience. Your courage, tenacity and humor are an inspiration.

Rare tumors / Urachal Carcinoma

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Ganfighter translates WebCafé into Japanese

A note to the newly diagnosed: Learn more: staging and grading - non muscle-invasive bladder cancer - muscle-invasive bladder cancer - Abbreviations used

Bladder Cancer-Not Just for Old Folks!

- Christine - 27 and pregnant with TCC
- Roger Barton -35 with muscle-invasive bladder cancer.
- Paul H. - 36 with T1, G3 papillary tumor (2cm) with CIS.
- Alana and Tom Steinmetz - Alana's dx: 36, high grade TCC and pregnant
- Young people share - Al age 45, Kelly, 38 and Donna age 44

Non muscle-invasive TCC

- Allison - Non muscle-invasive, low grade bladder cancer
- Ken Hulse - hematuria for two years before diagnosis, clean for five years
- Paul R BCG for high grade TCC/CIS
- Fred BCG+IFN followed by systemic chemo for muscle-invasive TCC
- Brian Gulino carcinoma-sarcoma of the bladder and BCG
- Carole Smith Fighting since 1994-BCG, Mitomycin, many TUR's
- Pat Silveria Keeping TCC in check with BCG + immune stimulants
- Paul Carr Refractory CIS/Valstar
- John Stroop BCG, BCG+IFN, BCG+IFN+IL2, Mitomycin C - staving off Cis since 1997
- Gary's BCG diary
- Rosie - BCG, watchful waiting vs. surgery, bi-polar instrument, Mitomycin C

To RC, or Not to RC… … How one man with Ta, Grade III TCC+CIS came to his decision to have a radical

cystectomy after seven opinions - Read Dan's Story

Muscle-invasive Bladder Cancer

Cystectomy with ileal conduit and external appliance

- Diane - 20+ years since surgery and still doing well

Cystectomy with continent internal reservoir (pouch)

Female:

- Sylvia Ramsey Long term survivor with Indiana pouch-poet and patient advocate [See also: Sylvia L. Ramsey Poetry for Bladder Cancer www.sylvialramsey.com]

- Karen J Pouch Woman Speaks- new chemo protocol from MSKCC followed by cystectomy/Indiana Pouch

- Kathy Leslie I Have No Bladder (Indiana Pouch)

Male:

- Bill Lanius: One Lucky Geezer Bill tells about getting the Florida pouch

- Ben Olsen Long term bladder cancer survivor (Kock pouch)

Cystectomy followed by (urethra-sparing) neobladder

Male:

- Tim - Nerve-sparing success story!

- Captain Dave 47 yrs; T1-G3 - RC, post op pathology: T2a-G3

- Ken Z: "I went into surgery with aggressive high grade stage T1 and came out with aggressive high grade stage T3aN0Mx."

- Robert Happy Neo-bladder recipient

Ken G Neobladder at age 46

- Larry Cystectomy, neobladder followed by M-VAC after p53 tested positive at USC/Norris
- Bill K. Continent reservoir from Skinner/USC Norris

Female

- Cindy's Tale- neobladder, 2005
- Enid's Tale Hautmann neobladder
- Neobladder Woman Anonymous contribution
- Linda's Story

Muscle-invasive Bladder Cancer-Bladder Sparing (TUR+radiation+chemo)

- Mike Mann 'Combined modality'

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} - March 2009 makes it ten years out, and still doing well.

- Cyndi - a woman's experience with combined modalities, treatment failure and subsequent bladder removal

Upper tract TCC - transitional cell carcinoma of the renal pelvis (Kidney TCC) and/or ureter

- Seth Brilliant TCC of the renal pelvis

- Paul S. Morton Jr Surgery for TCC of the renal pelvis and ureter, BCG treatments for TCC bladder

- Sally Surgery, chemo for TCC bladder, renal pelvis and ureter

Metastatic bladder cancer

- Susan - Delayed diagnosis, stage IV, near New Orleans post Katrina

To contact any of the above authors who have chosen not to include their email address, you can send questions or comments to the webmaster for forwarding.