A Dosimetrist’s Sarcoma Journey

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MD Anderson @ Cooper Cancer Center
Introduction

• Dosimetrist for over 35 years
• CMD in 1989 – Baltimore
• Worked at Virtua Memorial Hospital 33 years
• Chief of Medical Dosimetry @ MDA/Cooper 3 years
• AAMD Region IV Director 4 years
• AAMD President (Cycle 2010 thru 2012)
• Chaired and Wrote much of the P40 document Chronicling the 40 year history of the AAMD.

Life Changing Events

• 1865 – American Civil War

Not me!
Life Changing Events

- 1963 – Kennedy Assassination
- 1969 – Apollo Moon Landing
- 1973 – Fall of Saigon; End of Vietnam War
- 1986 – Challenger Disaster
- 1994 – OJ Bronco Chase
- 2001 – September 11: Twin Towers Come Down
- 2018 – Sunday February 4th...

Life Changing Events

- Philadelphia Eagles Win Super Bowl

Not Me!
Life Changing Events

Here’s one that might be unfamiliar to the rest of you but it’s a day that changed my life in an instant…

June 24th, 2011

That is the day that the knot in my distal thigh that I had ignored for well over a year presented itself as a huge, menacing

Sarcoma!

The “Pulled Muscle”

• Late in 2009, I was Bike-Riding...
The “Pulled Muscle”

- Snap in L Distal Thigh
- Had pulled muscles many times over the years
- Saw a General Practitioner in November 2010 (Over 1 year later)
- Both felt it would resolve

2011 - A Special Year

- June 2011 – AAMD Annual Meeting in St Louis – As Prez-Elect, I had put in a lot of work on that meeting
- August 2011 – I was to become the President of the AAMD
- Youngest Son to graduate college (University of Oregon)
Spring 2011

- Wife notes leg mass growing – Makes appointment for me
- Orthopod 5/19; MRI as an afterthought

**Impression and Plan:** At this point, his wife was concerned about it. I think it is reasonable to get an MRI of this thing and find out what we are dealing with. We will use gadolinium just to confirm that. I would like to see him back again with the results of the MRI and review that with him.

Electronically signed by John M. Gray, MD on 05/20/2011 at 21:50:57

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Spring 2011

- I delay – Fly to Stl 6/9 AAMD conference
Spring 2011

• Sunday 6/12 – Fly to Eugene for graduation

• Return home – Wife insists I get MRI before authorization expires!

MRI Discovery – Friday 6/24/11

• Arrive at work and head to MRI department
• MRI Chief (Mike) asks why I was there
• Mid imaging, Mike mentions over intercom that he will take me for reading
• I dress; Mike walks me to Radiology
• Images on monitors in front of Radiologist
MRI Discovery – Friday 6/24/11

• Distal Femur – Huge, Angry Mass

• “So sorry - Sarcoma – No doubt!”

Sarcoma Stats/Facts

• Arise in muscle, cartilage, fat, bone whereas most malignancies such as Lung/Colon/Breast arise in epithelial tissues - Carcinomas

• Rare – Few predictive factors:
  – Not confined to specific age group
  – Evenly distributed between men/women
  – Many High Grade bone Sarcomas (Ewings/Osteo) more prevalent in children
Risk Factors

• Some data supports certain risk factors
  – Genetics
  – Previous Radiation
  – Immune system abnormalities
  – Lymphedema
  – Chemical exposure

Statistics

• 2016
  – 12,310 diagnosed in the US
  – 1% of 1.5 Million newly diagnosed Ca cases
  – 5000 approximate deaths
Immediate Aftermath

- Dazed and confused – Find my way to Rad Onc
- Announce “Sarcoma” to Dr B & Mike
  - Dr B; Rad Onc & Dear Friend
  - Mike Walsh; Physicist & Dear Friend

Immediate Aftermath

- Dr B runs to Radiology to discuss with Dr Kwak
- My thoughts – How do I tell Wife/Sons?
- Dr B & Dr Ari independently locate “Go – To” guy in Delaware Valley
  - Dr. John Abraham
- Dr B makes appointment
- I drive home
Immediate Aftermath

- Karen (Wife)
  - A lot brighter than I am
  - Fine this AM; Now I am a Cancer patient
  - Karen working; I try to sleep
  - Finds me in bed; knows in bones bad things await
  - Upset and overwhelmed; Does not utter most painful of words – “I told you so!”
  - Hugged and cried quietly; My guilt intensifies

Immediate Aftermath

- Sons heading home
  - Chris – Motorcycle - San Francisco after JVC
  - Timothy – Car - Graduation from U of Oregon
Immediate Aftermath

• Spoke with Sons on phone
  • Did not lie but could not say much definitively
  • When I hung up phone...Only time I wept
  • Chris had taken up running in SF; We went out for his first 10K – Sarcoma Awareness Race
• Spoke with Parents and In - Laws; could not tell them anything specific.

Weekend After Becoming a Ca Patient

• What do you do?
  – Consult internet for anything/everything Sarcoma
  – Purposefully avoid internet information
  – Contemplate “what ifs”
  – Castigate yourself for ignoring signs
  – Act “Normal”
  – Consider “Peripherals”
    • Life Insurance – Will
    • Health Insurance - Coverage
Dr John Abraham – Rothman Institute

- Weekend Research
  - Harvard Undergrad
  - Yale Med School
  - Harvard Residency
  - Mass General – Fellowship Orthopedic Surgery
  - Director of Musculo-Skeletal Oncology Program TJUH

- Shocked at his age
- Listened attentively; Compassionate and Kind
- Gave a very preliminary Dx of Sarcoma

Biopsy

- Biopsy able to be performed that day
- Dr. A explained – Must be extremely careful
- I’m told it will be painful – No lie!
- Determined not to move
- Assistant takes specimen directly to Pathologist
- Results – Week to 10 days
How to Kill “Week to 10 Days”

• What would you do? I chose to go to work
• CoWorkers – 30yrs +; They had an inkling
• Hungry, Hungry, HIPPA and me...
  – Cancer Patient
  – Husband
  – Father
  – Dosimetrist
  – Coach
  – CoWorker

Dr B - Maine

• Explained what went on with Dr. Abraham to Dr. B and Mike
• Dr. B calls me an “Idiot”...Nicely
• Dr. B – Boss/Friend/Much younger than I
• Sends me to Maine cabin
Dr. B - Maine

• Peace and solitude; Perfect setting as we awaited Bx results

Imaging Studies

• Underwent first of dozens of CT Chests
• Registrar – Why are you here today?
• CJM – “They are looking for Mets in my Chest”
  – Did I just say those words...Or someone else?
• Dr. B – Now in Maine; Knows exactly when I am on CT table and when images are read
Oddest Text All Time!

- Cell phone vibrates as I head to Reading Room
- Speak w Radiologist; All clear with exception of “Most Likely” benign Granulomas
- Read odd text; “So glad you don’t have Mets”
- Must understand our relationship and just how hard it is to use your cell phone in Maine
- Husband (Urologist) tells me she was a wreck until she spoke with Radiologist. Still touched

Diagnosis

- F/U w Path posted exactly 2 weeks after Bx
- Large MyxoFibro Sarcoma in Vastus Medialis
- Low Grade/High Grade
- 11.5cm Sup/Inf, 6cm Lt/Rt, and 4.5cm Deep (4.5”/2.5”/1.8” for metrically challenged!)
- Metastatic course – Initially local then distally to Lungs.
Treatment Recommendation

• Immediate initiation of Ext Beam Radiation
  – Suspend growth
  – Sterilize periphery
  – Reduce possibility of surgical spread

• ? Surgical removal ASAP – “Get this nasty thing out of my leg!”

• “How about chemo?”

Cracker Barrel Consultation

• Left Philly and drove to Cracker Barrel (MPB!)
Cracker Barrel Consultation

• Called Dr. Ari
• Very close – 30+ yrs together

• Insisted I come over right away for Sim
• Gnawing issue – Tx by Dr. B
  – I work there physically – Tough on Staff
  – Somewhat older equipment
• Called her to apologize/explain

Simulation

• Dr. Ari warned staff – “VIP” coming in
• Reception dilemma – Where to go?
• Entered into Mosaiq – Surreal
• Exam room with Dr Ari; Sad Eyes
• Radiation course – 50Gy/25Fxs – Standard
• Highlighted Bx site as instructed by Dr. Abraham
Simulation

- CT Sim personnel – I had trained them! Very emotional – Felt terrible for them
- Sim itself - Unremarkable
  - Wire on Bx site
  - Immobilization device created
  - Tattoos given
- F/U apt for V-Sim and the 25 Fxs

Dosimetry

- Do I do my own plan? I chose not to
  - Felt “Disconnected”
  - Horrible burden for Dosimetrist that did plan
  - 3 Physicists checked plan
  - 5 Radiation Oncologists involved
- Plan went thru Chart Rounds – Surreal
Treatment Plan

• Size creates difficulty – Rad Onc Guidelines call for large margins
• VMAT considered but early days
• Segmented field set then collimator turned 90 degrees for a wedge set – 4 Beams in all
• Limitations of portal imager – Large fields split into “Upper/Lower” so 8 fields on portal imaging days
• Could I have improved plan?

Treatment Day

• Surreal – In a daze; How can this be?
• Checked in and put on gown
• Where do I sit? Waiting room? Dosimetry?
• Thanked dosimetrist who did my plan
• Therapist – JoAnn – Came and called for me
  – 30 yrs with her; Shared laughs and life with her
  – Obliquely my boss at one point
  – Could not have been a more comforting face
• Mosaiq read “Moore, Christopher J.” Huh???
Treatment Day

• Told staff to relax and do as they’ve been taught
• Climb onto table and fit into cast
• Positioning complete; parameters verified
• Therapists head for the door – “Wait” I think; This can’t be right! Had done this a thousand times...But I don’t stay in the treatment room!

Treatment Day

• Short burst as initial image taken; motors whirr as Linac prepares for 2nd exposure.
• I have a thorough understanding but seems like an odd dream or movie sequence
• Therapists return to verify positioning & parameters – Only 7 more images to go!
• Now it becomes clear the issues my size presents...
Treatment Day

• By the 3\textsuperscript{rd} or 4\textsuperscript{th} image, my leg begins to shake involuntarily...I am petrified.

• Have been a Dosimetrist a long time; I understand that we have closed our margins significantly as imaging studies became more precise. The back side of that story is that the patients MUST remain perfectly still or we could “miss” the target, Knowing this, how is it that my leg refuses to remain still!

Radiation Completion

• Other than Port Film days, treatments fine
• Little to no skin changes or side effects
• Follow up MRI as I neared completion; little change – That was expected!
• Completed treatment on a Friday; saw Dr Abraham Monday.
• Slotted me for surgery in 1 week!
Surgery

• Surgery was an unknown; prepared for anything up to and including amputation
• Excision would involve fairly wide margins; beyond that, it was a mystery to him as well:
  – Had the tumor broken through the fascia?
  – Was there bony involvement?
  – Was the lesion fully compartmentalized or had it spread locally?
• I found the field of Orthopedic Oncology fascinating

Surgery

• Most difficult part – Knee Joint
  – Historically, remove entire knee joint w replacement
  – Dr Abraham helped pioneer a technique to thoroughly evaluate bone to avoid replacement
  – If partial involvement, he had a cadaver bone on hand to insert if required.
Surgery

• 9/11/11 – “Radical excision of Lt Thigh Sarcoma greater than 10cm”
• Several encouraging signs:
  – Mass had not penetrated the capsule
  – Contained entirely in Vastus Medialis
  – Clear plane (2mm) between the capsule and the femoral periosteum

Post Operatively

• Pathology came back very quickly – As Dr Abraham predicted, it was a “High Grade” lesion.
• “Significant” necrosis found
• 21cm x 11cm x 8.5cm (8”/4.5”/3.5”) specimen excised to include bolused skin segment
• Very little Post Op Pain – TJUH anesthesia piloted a pain receptor program – Great!
• PT began Day 2 Post Op – I could walk!
Follow Up

- Dr Abraham warned that he needed to monitor my progress closely
- MRI Thigh & CT Chest every 3mths for 2yrs
- MRI Thigh & CT Chest every 6mths for next 3yrs
- Couple Milestones to shoot for:
  - No recurrence in 1st 2 yrs, risk drops significantly
  - 5 yr Marker as the marker for success

Meanwhile, Back with the AAMD

- My disease/treatment coincided with my AAMD Presidential year
- Seriously considered resigning
- My BoD/HQ staff could not have been more supportive
- Year went well; BoD quite understanding
- I may not have been very good but I gave it substantial time while recuperating!
Infection – Uh Oh!

• At 9mth mark, leg ballooned to 2x it’s size
  – Infection had set in
  – Leg looked awful; horrible for my wife
  – PICC Line inserted
  – Home infusion begun
  – Oddly, Dr Abraham remarked that there is anecdotal evidence that an infection within the first 2yrs post op was a positive indicator

Infection – Uh Oh!

• PICC Line and home infusion jeopardized capstone of Presidential year – Annual Meeting
• Convinced Infectious Disease MD to pull line and let me go on oral antibiotics
• Performed my duties with a cane at times and wife running down Oral Antibiotics when called for by treatment schedule
One More Torture for Wife

• Just as I hit the 2yr mark, a small defect was seen on F/U MRI

One More Torture for Wife

• Review of previous MRIs found this defect and the apparent growth in size
• Subsequent surgery
  – Bone Graft
  – Plate/Screws inserted
  – Path NED; Believed to be a small femoral fracture
Second Surgery

• Plates, screws, bone grafts - Oh hum...
• Guaranteed fun at the airport!

Today

• Pretty pleased to be here to give this lecture!
• Had promised my wife I would write this but wanted to wait out the 5yr mark.
• In these years:
  – Witnessed both my Boys marry incredible women
  – Eldest Son made me the happiest Pop-Pop ever
  – Spent these days with my HS sweetheart; Put her though a tremendous ordeal
Today

• I cherish my care team
  – Drs Abraham/Ariaratnam/Butzbach
  – Rad Onc staff
  – Surgical Team
  – PT Torturers
• Remain angry that I had to rely on them
• Can’t seem to forgive myself for ignoring this

Today

• I wear my “Cancer Badge” differently than some
• I refuse to use the “Cure” word
• I am not different than anyone else
• I am certainly not “Brave” for facing this
• This story has many heroes – But I’m not one of them!!!
Takeaways From This Lecture

• This disease does not go away for our patients
• Strict F/U – How does one move on with life?
• Every step I take reminds me I am a Ca patient
• Be careful when you think a patient is being difficult; we don’t know Day Care issues, money issues, bus routes, etc
• I work in the field and have always had “Good” insurance. I could write a book on the issues I faced with insurance companies.

Takeaways From This Lecture

• My position benefitted me greatly
• Was scanned/biopsied/consulted by a top Orthopedic Oncologist over 2 work days. How lucky I am to live so close to this sort of specialist.
• How many General Orthopedists would have tried to perform this biopsy/surgery?
What I Learned

• HS friend – Suzanne – Melanoma MDA patient
• “My Ca is liberating”
• CJM – “Huh”???
• “It has allowed me to not sweat the small stuff – Flat tire, cable out, missed appointment - None matters. I am here to enjoy my kids, breathe deeply of the fresh air that surrounds me, see the beauty of the world that envelops me and drink it all in!”

Final Point and I Swear I’ll Quit Talking

• The “Hero” of this story
Thank You for Listening!!!

• Any Questions?