WANT TO GET INVOLVED?

For Providers:

Synovial Sarcoma Tumor Board

Hosted by the Very Rare Malignant Tumors Program at the Children's Hospital of Philadelphia (CHOP) and Dr. Ted Laetsch.

Takes place virtually from 5-6 PM EST on the 4th Monday of every month.

Open to medical personnel only. Patients and their family members are not permitted to attend.

To request to be added to the email list and calendar invite, please email project manager Lauren Gutstein at **gutsteinl1@chop.edu**.

Children's Hospital of Philadelphia
RESEARCH INSTITUTE

For Patients:

Children's Hospital of Philadelphia

Spence Family Synovial Sarcoma Foundation

Synovial Sarcoma Registry and Biospecimen Repository

*Do you have or know someone diagnosed with **Synovial Sarcoma**?*

We want to better understand and treat it.

You can help.

How it works:

You give permission to access your
- medical records
- leftover tumor tissue
- blood/saliva sample

We use this data to advance research and improve outcomes for patients in the future.

Consent Form

For more information:
Study Website: https://tinyurl.com/synovialsarcomaregistry
SynovialSarcomaRegistry@chop.edu; (267)827-8145
Principal Investigator: Dr. Theodore Laetsch

WELCOME TO THE INAUGURAL SYNOVIAL SARCOMA VIRTUAL CONFERENCE

March 1st, 2025

Hosts: Dr. Theodore Laetsch & Chas Spence

Children's Hospital of Philadelphia
Center for Childhood Cancer Research

Spence Family
Synovial Sarcoma Foundation

WELCOME MESSAGE
&
CONFERENCE OVERVIEW

CONFERENCE LOGISTICS

Asking Questions:

- Questions can be submitted via the chat throughout the session.
- Some questions will be answered live during the Q&A segment.
- Chat monitors (Lauren & Dyani) will help filter questions for presenters.

Technical Support:

- If you experience audio/video issues, try refreshing your connection.
- For ongoing issues, message a chat monitor for assistance.

Disclaimer:

- *This conference is for educational purposes only.*
- *This will be recorded. Please avoid sharing personal details that you may not want to be public.*
- *We cannot provide personalized medical advice during this event.*
- *For specific medical concerns, please consult your healthcare provider.*

AGENDA

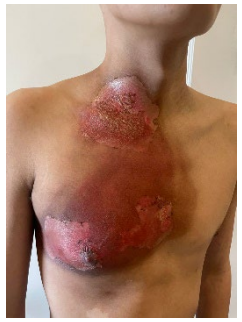
- Callan's Story and Spence Family Advocacy
- Clinical Trial & Treatment Updates
- Radiation Therapy Options
- TumorGlow in Adult and Pediatric Surgeries
- Synovial Sarcoma Registry Preliminary Data
- Research with Mice Models

CALLAN'S STORY

- In 2022, Callan Spence, 16 y/o son of Laura & Chas Spence was diagnosed with Synovial Sarcoma, a non-metastatic 16cm tumor in the upper right thoracic region
- 7 hospitals were engaged to evaluate treatment options
  - 2 hospitals deamed tumor 'inoperable'
  - 2 hospitals offered comprehensive Chemotherapy (AIM), Radiation (25 Doses) and Surgery (10-hrs)
- Following AIM treatment, surgeons removed rt upper lobe, rt subclavian artery, rt jugular vein, phrenic nerve, vagus nerve, subclavian vein & rt recurrent laryngeal nerve, along with the tumor. Callan remained NED for 2-years

Chemo

Radiation



Post Op

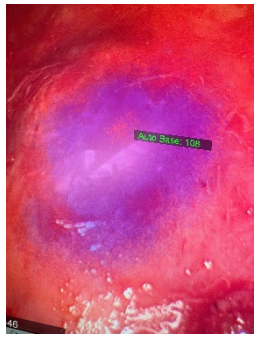
Recovery

CALLAN'S STORY (CONT)

- In July 2024 - exactly 2-years post surgery - a lesion was spotted near the original tumor bed on scans
- Biopsy indicated Synovial Sarcoma & surgery scheduled
- Callan underwent 4-hr surgery to remove malignant lesion and remaining pleura utilizing 'Tumor Glow' technology
- Following R0 surgery, he underwent 30 doses of radiation, followed by 800mg of Votrient
- Callan presented as NED 6 months following surgery & radiation. He will continue Votrient until he remains NED for 3 scans

Tumor Glow Infusion

Surgery w/ Tumor Glow



Post Op

Upenn Lab Tour

SPENCE FAMILY ADVOCACY

- Following Callan's initial surgery in June 2022, Chas Spence began scraping Facebook sites to uncover 'passive' Synovial Sarcoma cases around the world
- To collect 'active' data, he created a new Facebook page, now called "Synovial Sarcoma Foundation Community," whose mission is to collect patient data and treatment plans to share with the community via a required sign-up survey.
- The Facebook survey, which now has over 230 active participants was presented to CHOP, including Drs. Ted Laetsch & Stephanie Fuller in late 2022.

Primary Tumor	%
Shoulder	3%
Back	4%
Stomach	4%
Foot	9%
Head/Neck	9%
Pelvis/Butt/Hip	10%
Arm	13%
Chest	17%
Leg	31%

Age	%
0-9	2%
10-19	18%
20-29	18%
30-39	27%
40-49	17%
50-59	12%
+60	6%

Chemotherapy	%
After Surgery	29%
Before Surgery	21%
Both Before and/after surgery	20%
I did not receive Chemo	23%
I received Chemo, but DID NOT have surgery	6%

No Evidence of Disease (NED)	%
Less than 1 Year	31%
1-2 Years	31%
1-3 Years	7%
3-5 Years	9%
5-10 Years	13%
More than 10 Years	9%

SPENCE FAMILY ADVOCACY

- In early 2023, Laura & Chas Spence committed $650,000 to launch the Spence Family Synovial Sarcoma Foundation - in collaboration with CHOP & HUP - to lead the world in improving the standard of care and outcomes for Synovial Sarcoma patients
- Over the next 2 years, the Foundation has raised over $1.7M to support the following initiatives:
  - Launching the National Synovial Sarcoma Tumor Board
  - Development of the National Synovial Sarcoma Registry and Biorepository
  - Fully fund the Pediatric TumorGlow Clinical Trial
- In 2025, NJI Media, a global Marketing & Public Relations firm, with clients such as PhRMA, META & WWF, committed to partner with the Synovial Sarcoma Foundation to supercharge our advocacy work and help put Synovial Sarcoma on the global radar.

SYNOVIAL SARCOMA

Lessons learned and the road ahead

Theodore Laetsch, MD
Jacquelyn Crane, MD

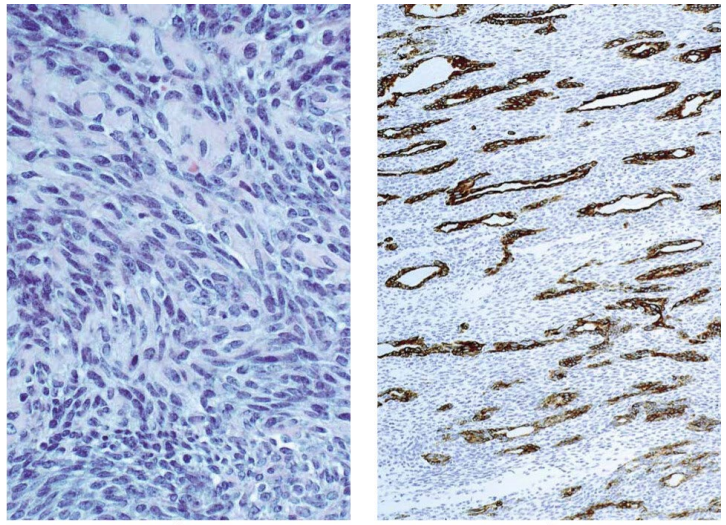
Children's Hospital of Philadelphia
Center for Childhood Cancer Research

Spence Family
Synovial Sarcoma Foundation

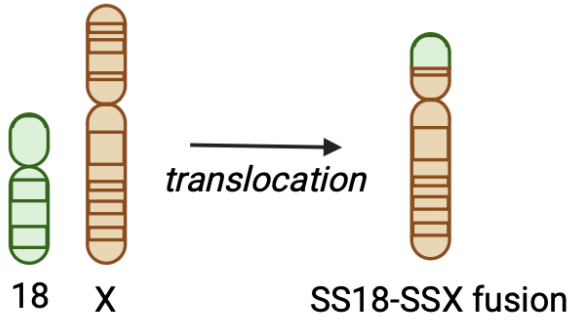
BACKGROUND

EPIDEMIOLOGY AND DIAGNOSIS OF SYNOVIAL SARCOMA

- Estimated 600 cases per year in the US
- Can occur at any age but most commonly affects children and younger adults
- Often presents with nonspecific symptoms including swelling or pain
- Provider with sarcoma expertise important to plan optimal tissue sampling approach for pathologic diagnosis
- Propensity for metastasis
  - MRI (or CT) of primary site
  - Chest CT
  - +/- whole body FDG PET CT or MRI



monophasic biphasic



Kawai et al., NEJM 1998
Translocation figure made with biorender.com

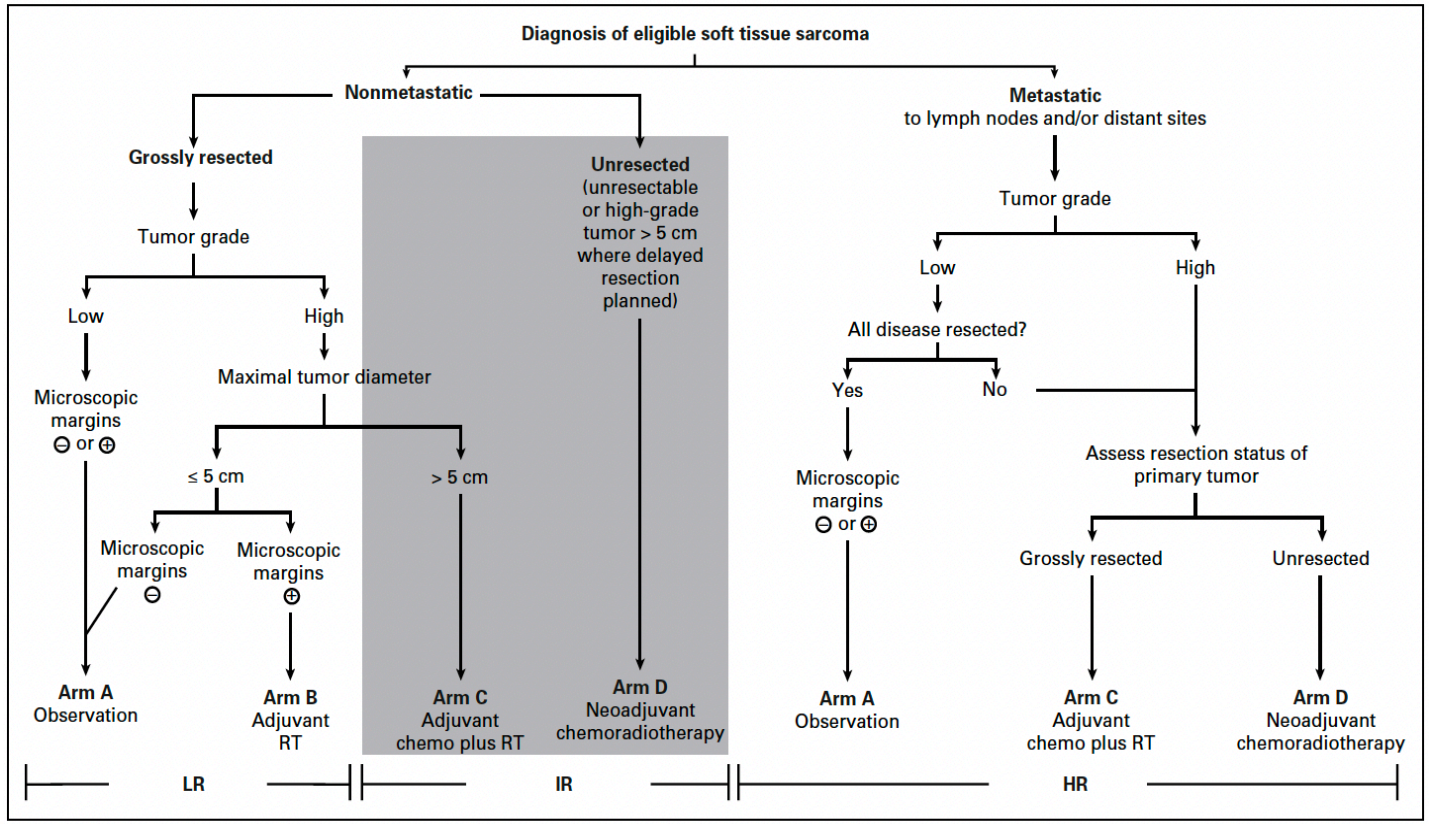
PROGNOSTIC FACTORS

- Presence or absence of metastatic disease
- Primary tumor size
- Pathologic grade (grades 1-3)
  - Pediatric Oncology Group (POG)
    - Grades 1 and 2 are considered low-grade; Grade 3 is considered high grade
  - Fédération Nationale des Centres de Lutte Contre le Cancer (FNCLCC)
    - Grade 1 is considered low-grade; Grades 2 and 3 are considered high grade; synovial sarcoma is by definition at least grade 2 on the FNCLCC system
- Surgical resectability / surgical margins
  - R0 resection - No residual microscopic disease
  - R1 resection - Microscopic residual disease
  - R2 resection - Gross residual disease

STANDARD OF CARE OF SYNOVIAL SARCOMA AT INITIAL DIAGNOSIS

CARE OF PATIENTS WITH NEWLY DIAGNOSED SYNOVIAL SARCOMA

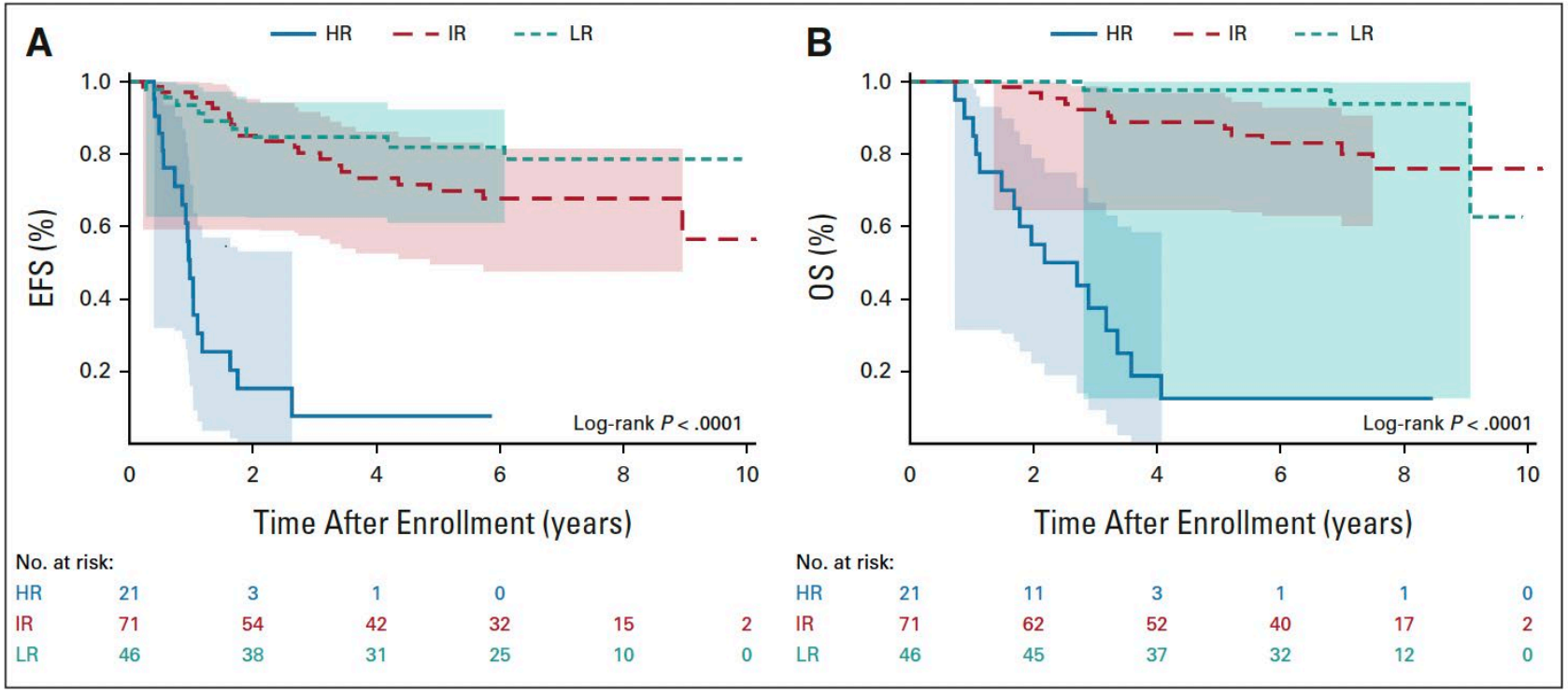
- Approach is risk adapted and may include
  - Surgery
  - +/- Radiation
  - +/- Chemotherapy (ifosfamide/doxorubicin)
- Ideally, multidisciplinary team input is provided prior to treatment initiation to guide optimal approach and timing
- There are nuances that may require adjustments to this approach for each individual



Children's Hospital of Philadelphia
Center for Childhood Cancer Research

Spunt et al., Lancet 2020
Venkatramani et al., JCO 2023
Kraybill et al, Cancer 2010
Mullen et al., Cancer 2012

CURRENT OUTCOMES



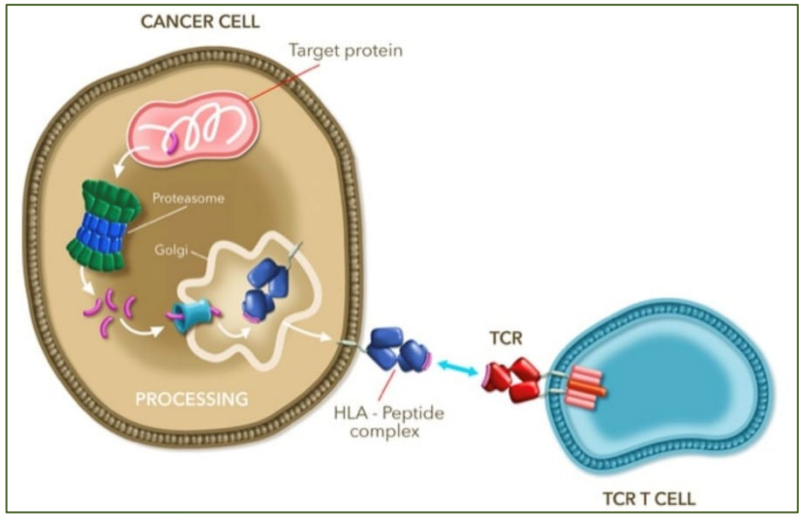
- Post treatment surveillance is needed due to risk of disease recurrence

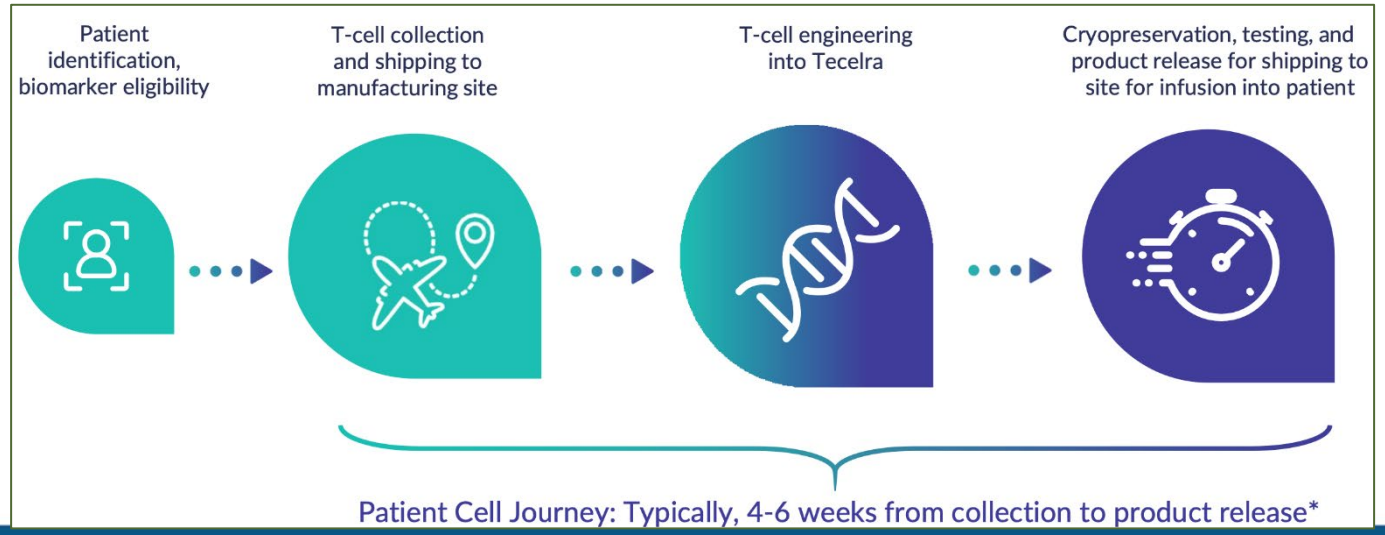
Venkatramani et al., JCO, 2023

RECENTLY APPROVED TREATMENT, OTHER TREATMENTS IN DEVELOPMENT, AND OTHER TREATMENT OPTIONS

TECELRA (AFAMITRESGENE AUTOLEUCEL)

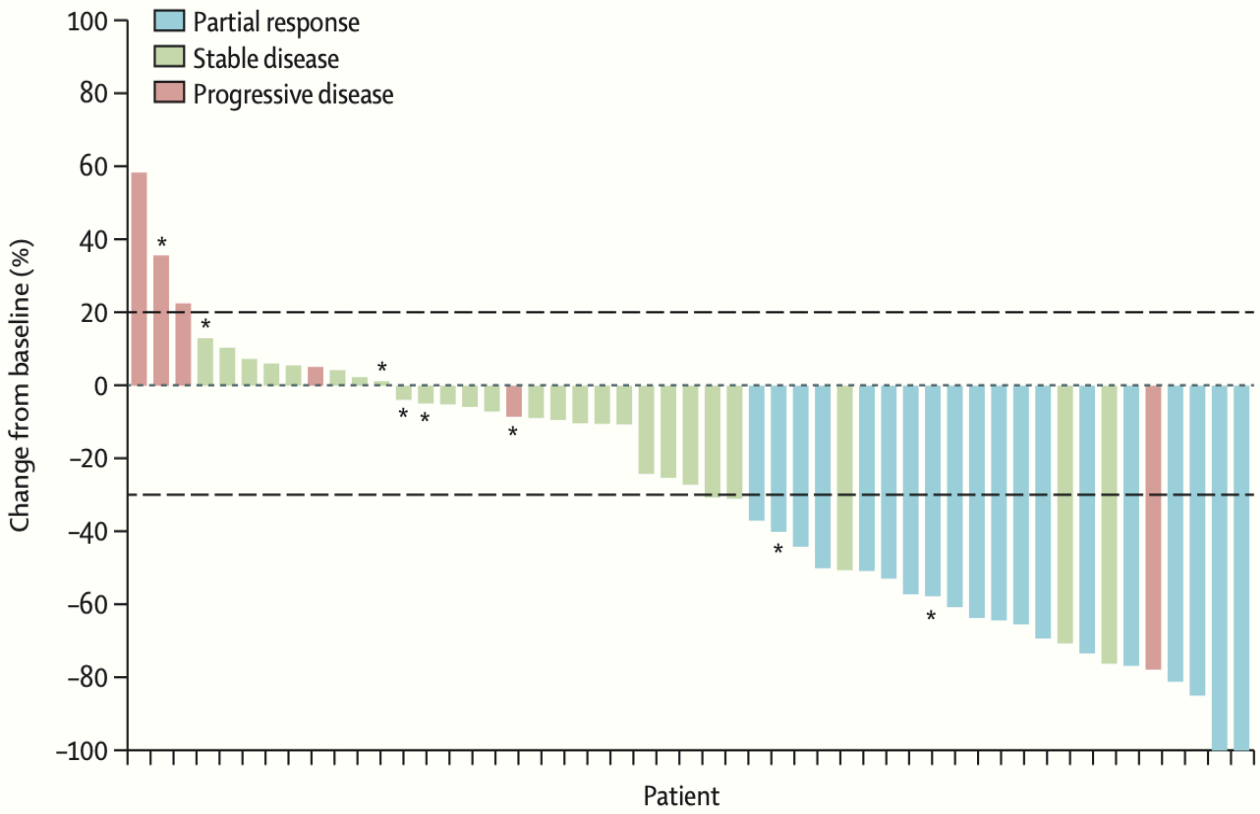
- Approximately 70% of synovial sarcoma express melanoma-associated antigen A4 (MAGE-A4)
- TECELRA is a MAGE-A4-directed genetically modified autologous T cell immunotherapy





OUTCOMES AND STATUS OF TECELRA

- FDA approved for adults with unresectable or metastatic synovial sarcoma who:
  - Have received prior chemotherapy
  - Are HLA-A*02:01P, -A*02:02P, -A*02:03P, or -A*02:06P positive
  - Have MAGE-A4 antigen tumor expression



Each bar without a start represents a patient with synovial sarcoma

D'Angelo SP, et al. Lancet 2024

ONGOING TRIALS AND TREATMENTS IN DEVELOPMENT

- SPEARHEAD-3 Pediatric Study:
  - Evaluating the safety and efficacy of afamitresgene autoleucel in HLA-A*02 eligible and MAGE-A4 positive subjects aged 2-21 years of age with advanced Synovial Sarcoma (and MPNST, Neuroblastoma, or Osteosarcoma)
  - Enrollment temporarily suspended
- IGNYTE-ESO trial:
  - Evaluating Letetresgene autoleucel (lete-cel) which an autologous engineered T cell receptor therapy targeting the NY-ESO-1 cancer testis antigen
  - Interim results with overall response of 39% in synovial sarcoma, final results pending
- Treatments targeting PRAME in development

D'Angelo SP, et al. ASCO abstract 2024

OTHER TREATMENT OPTIONS IN SETTING OF RECURRENCE

OTHER TREATMENT OPTIONS

- Pazopanib (PALETTE trial)
- Regorafenib (REGOSARC trial)
- Other systemic options such as oral etoposide
- Local control options
  - Surgery
  - Radiation

Van der Graaf, Lancet, 2012
Berry et al., Cancer 2017
Mir et al., Lancet Oncol 2016

TUMOR GLOW FOR ADULTS WITH SARCOMA

Dr. Sunil Singhal, MD

Children's Hospital of Philadelphia
Center for Childhood Cancer Research

Spence Family
Synovial Sarcoma Foundation

Pulmonary Metastasectomy for Sarcoma

Sunil Singhal, MD

William M. Measey Professor, Thoracic Surgery

Vice Chair, Translational Research, UPENN Surgery

University of Pennsylvania School of Medicine

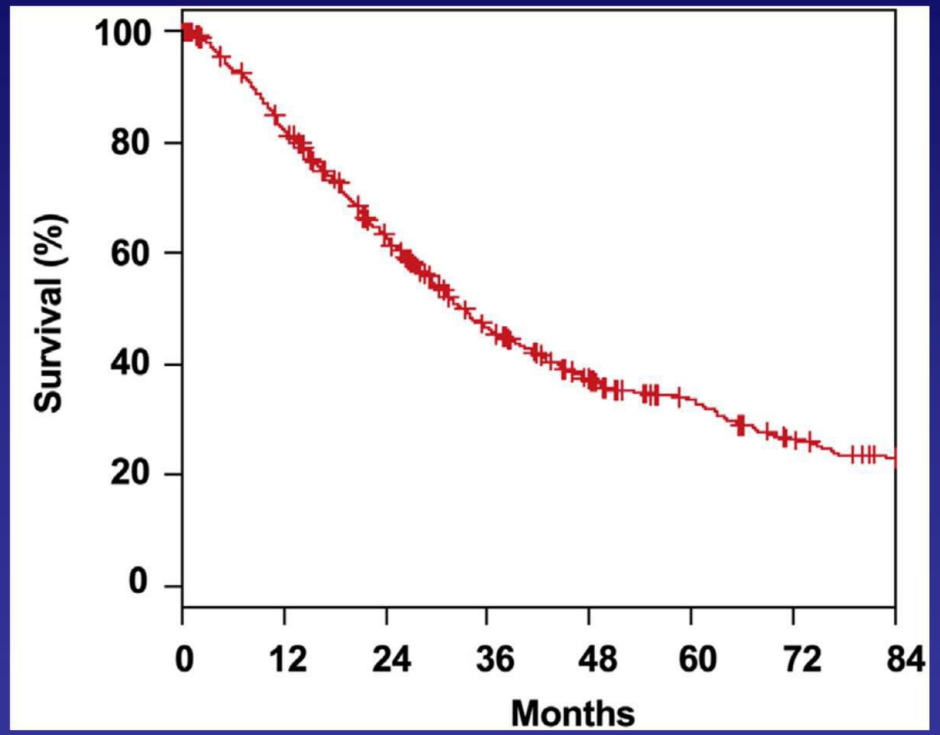
No disclosures

Pulmonary Metastasectomy

- Accepted procedure
- Indicated for sarcomas, colorectal, melanoma, renal
- Best predictors:
  - Disease free interval
  - Local control
  - Tumor size
  - Number of metastases

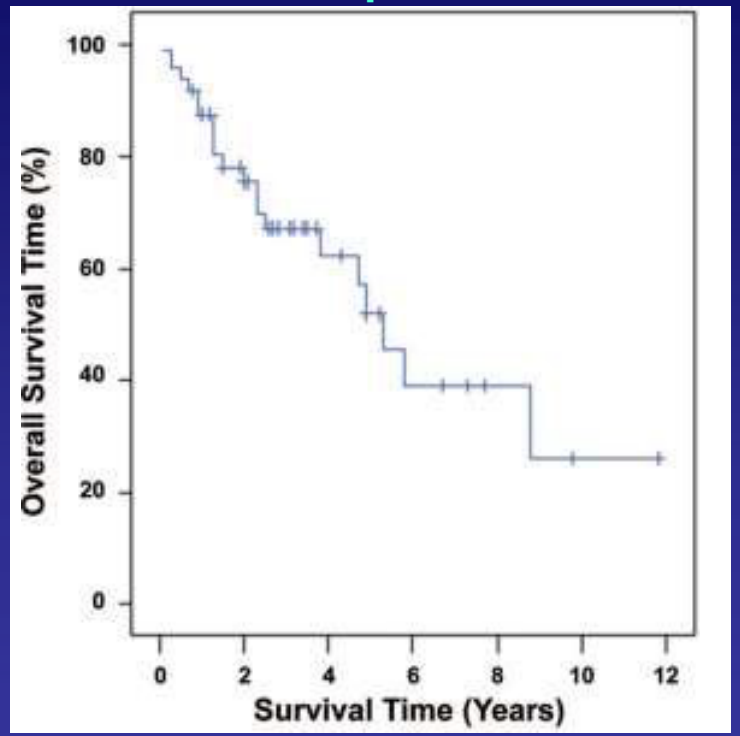
Sarcoma Metastasectomy

MSKCC Experience



Chudgar, *JTCVS, 2017*

Penn Experience



Predina, *JTO, 2011*

Clinical Problem

Sarcoma Metastasectomy

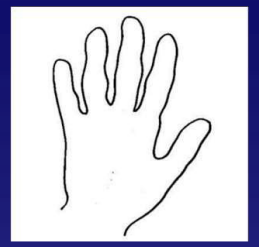
COMPLETE DISEASE CLEARANCE

Single most important predictor of outcomes.

Problem

Identification of all disease

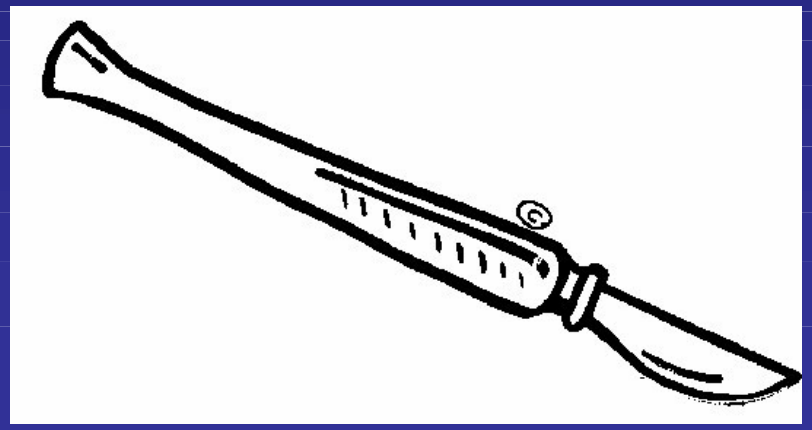
Why do surgeons have these problems?



Limited tools

A Surgeons' Challenge

No intra-operative tool has successfully improved the surgeons ability to find tumors over the last 200 years.



Intraoperative Molecular Imaging Solution

Hypothesis

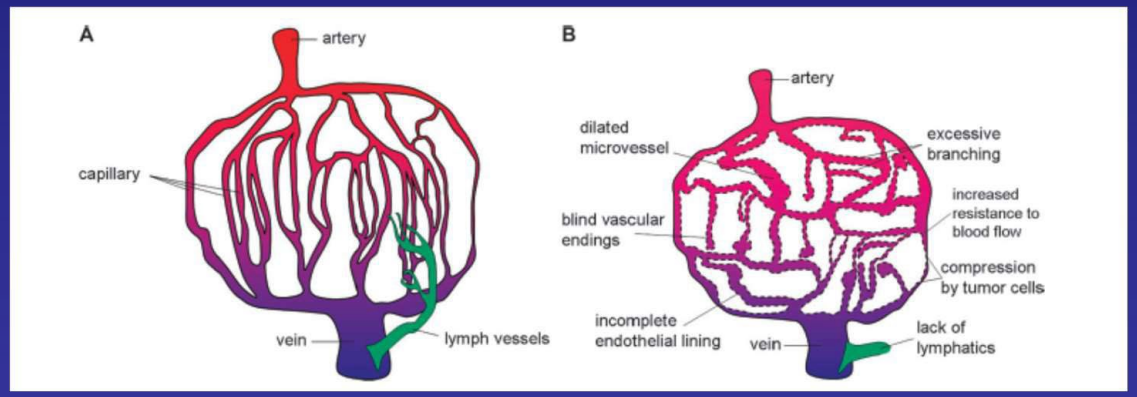
Near infrared imaging can improve detection of sarcoma metastases missed by

(a) preoperative CT imaging

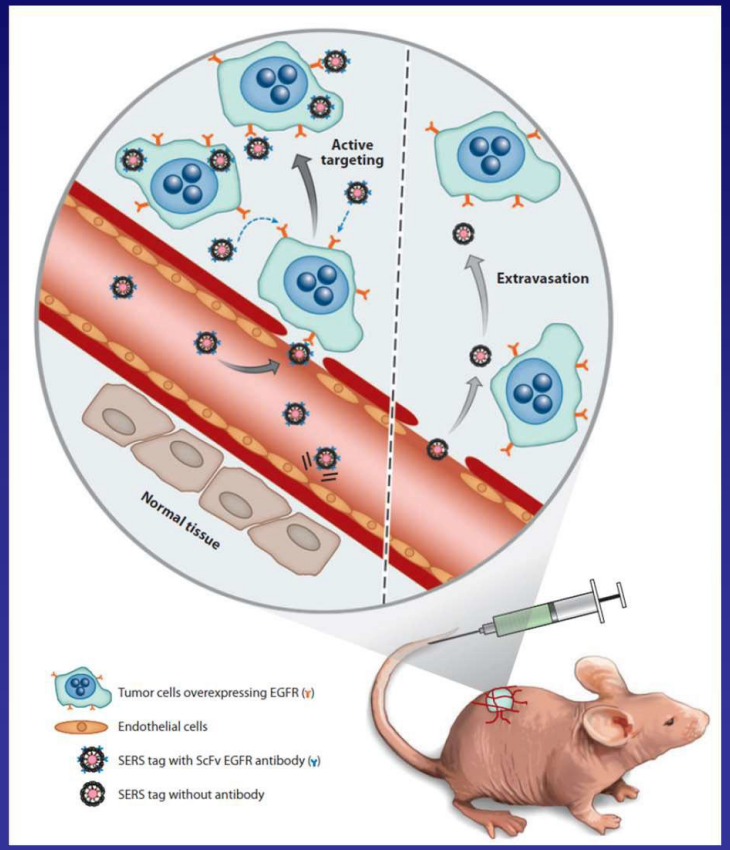
(b) intraoperative inspection

Tumor microenvironment

- Extensive production of vascular permeability enhancing substances
- Differences in capillary fluid transport



Enhanced permeability and retention effect



Nanotechnology Applications in Surgical Oncology

Sunil Singhal,[1] Shuming Nie,[2] and May D. Wang[3]

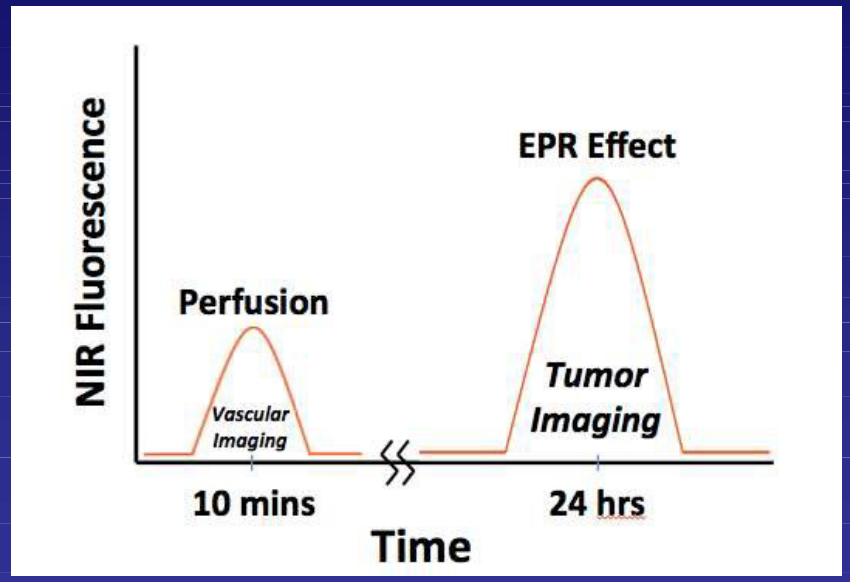
[1]Division of Thoracic Surgery, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania 19104; email: sunil.singhal@uphs.upenn.edu

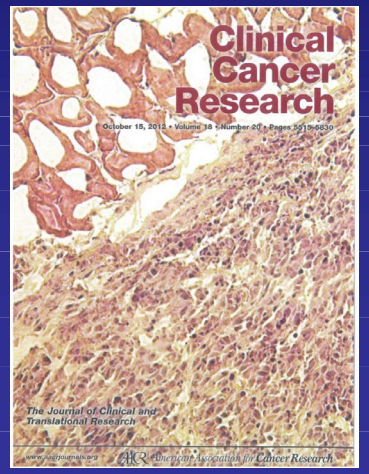
[2]Departments of Biomedical Engineering and Chemistry, Emory University, Atlanta, Georgia 30322; email: snie@emory.edu

[3]Department of Biomedical Engineering, Georgia Institute of Technology, Atlanta, Georgia 30332; email: maywang@bme.gatech.edu

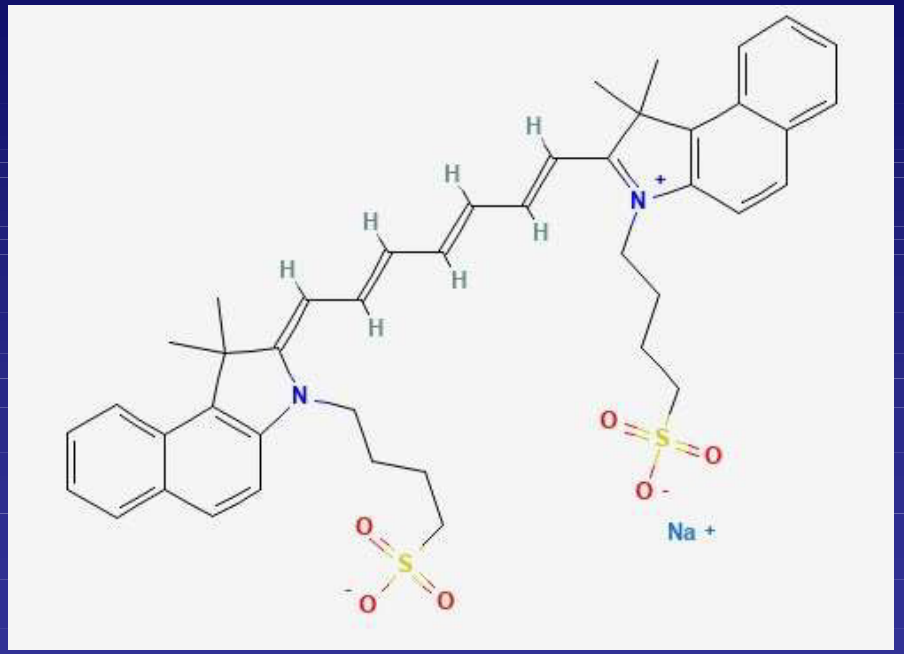
Annu. Rev. Med. 2010. 61:359–73

Seminal observation with ICG (2011)





Birth of TumorGlow

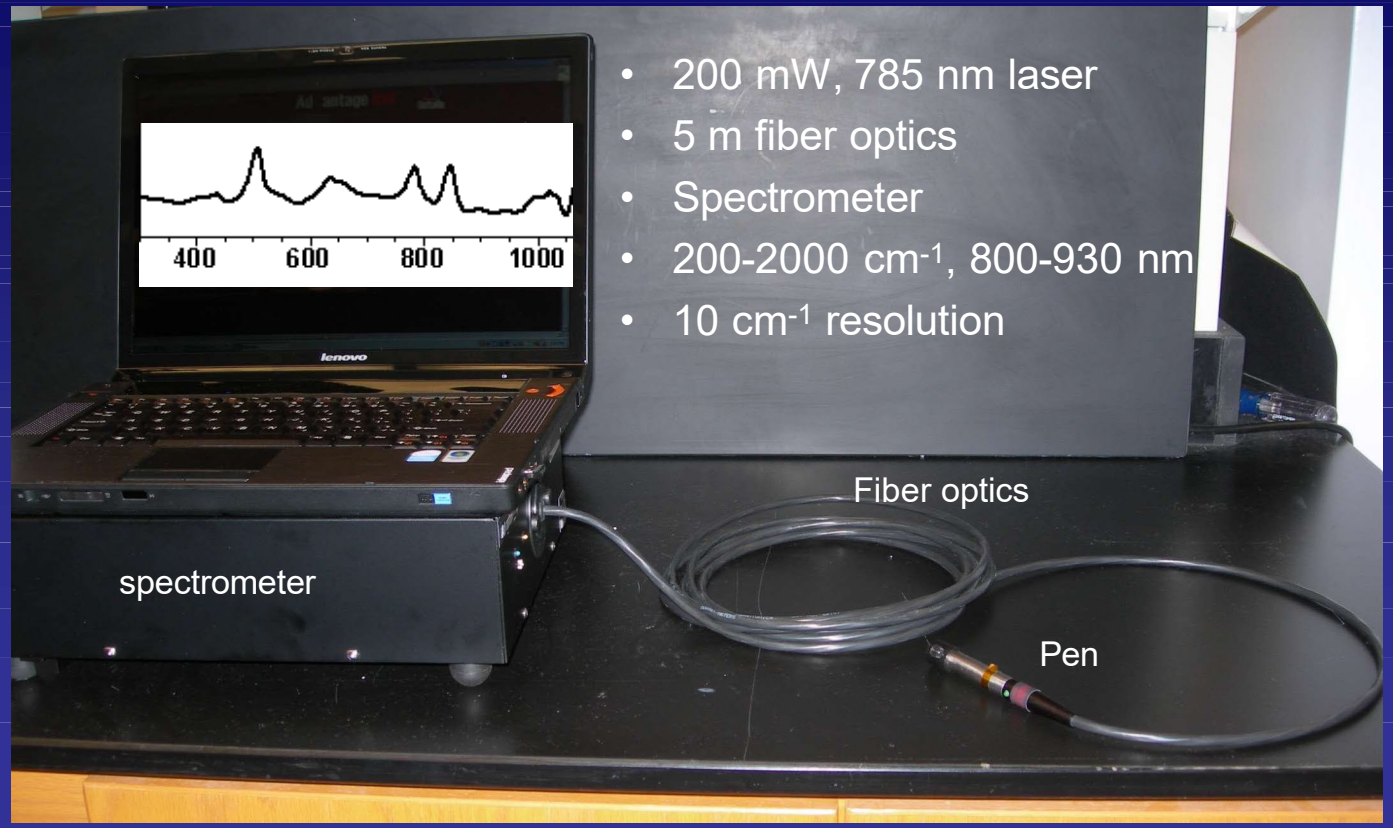


1 – NIR range
2 – small molecule
3 – EPR mechanism
4 – safe

High dose ICG
Mixed in water
Given day before

Singhal Lab, 2011

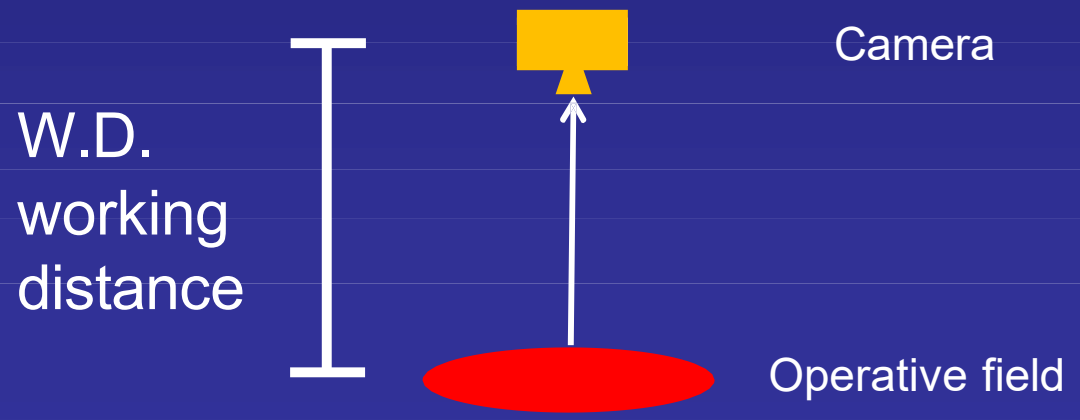
Raman (Spectro) Pen



- 200 mW, 785 nm laser
- 5 m fiber optics
- Spectrometer
- 200-2000 cm^{-1}, 800-930 nm
- 10 cm^{-1} resolution

Move towards optical visualization

$$\text{Light} = \frac{1}{(\text{W.D.})^2}$$



1st Generation Device: SPIIF

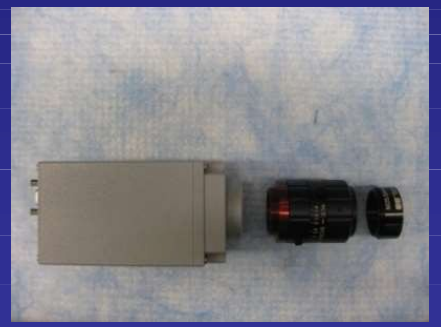


Table 1
List of SPIIF components with prices and various specifications.

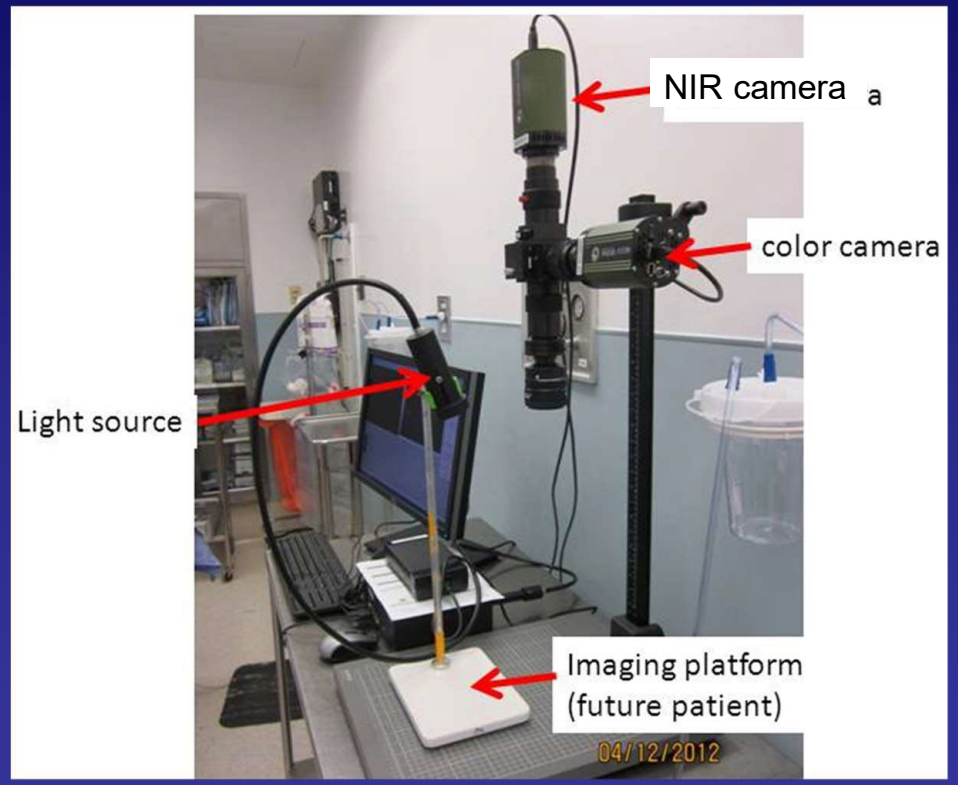
Prototype system specs	
Camera	
Weight	0.46 lbs
Cost	$1,595
Computer interface	USB 2.0
Power source	USB
Shutter	100 s to 10 s
Frame rate	10
Lens	
Price	495
Focal length	16 mm
Mount	C-Mount
NIR Transmission	to 1000 nm
Light source	
Cost	~$550
Spot size	10 mm
Power source	AC input
Heat sink	
Cost	$50
Power source	
Cost	$295
Metal plate	
Size	16 × 11 × 0.5
Filter holder	
Cost	$78
Max filter size	9 mm
Total weight	2.0 lbs
Total price	$3,200

$3,200

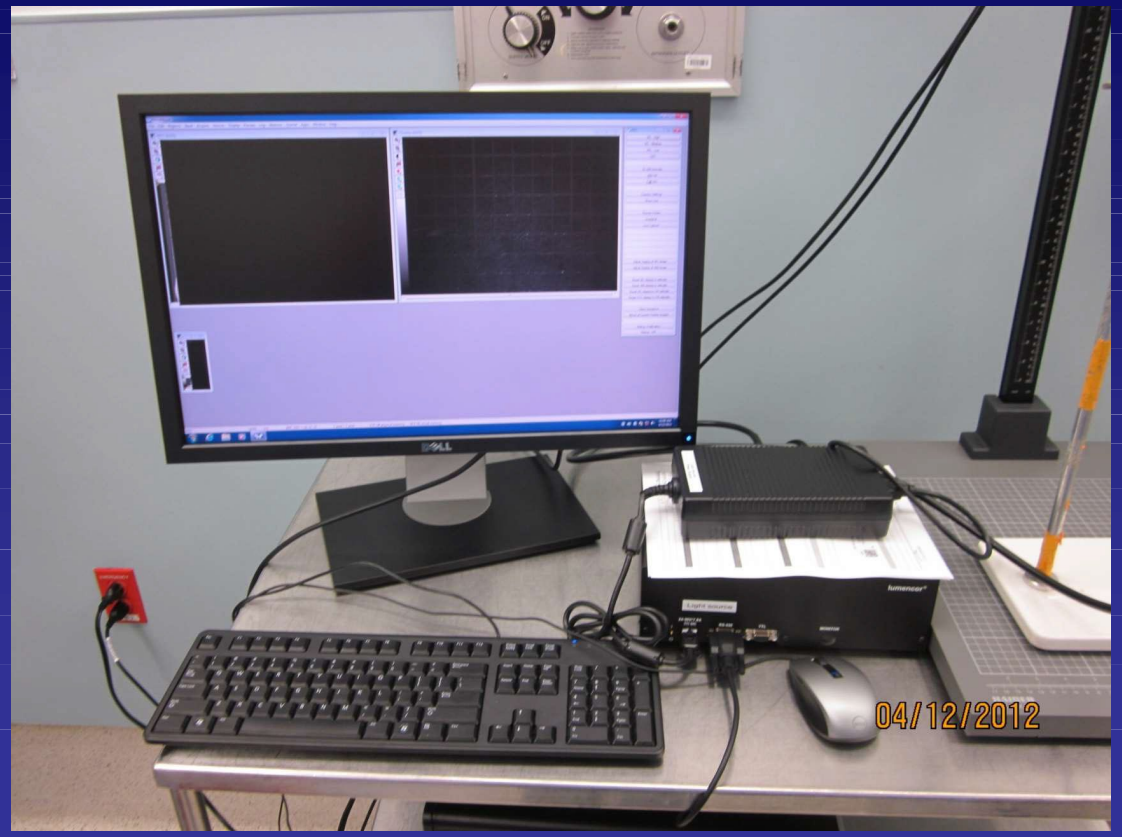
Small Portable Interchangeable Imager of Fluorescence for Fluorescence Guided Surgery and Research

Okusanya, 2013

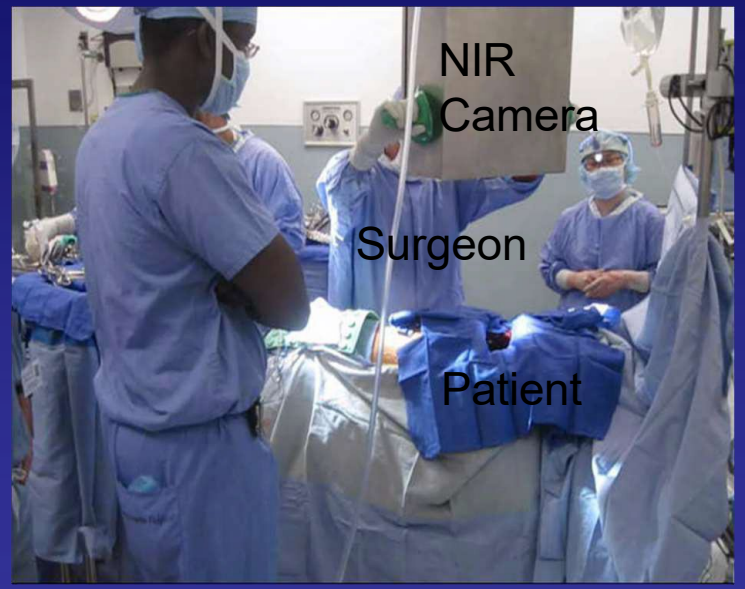
5th Generation Device: FloCam



5th Generation Device: FloCam



5th Generation Device: FloCam



Clinical Data

Inclusion Criteria

(n=30)

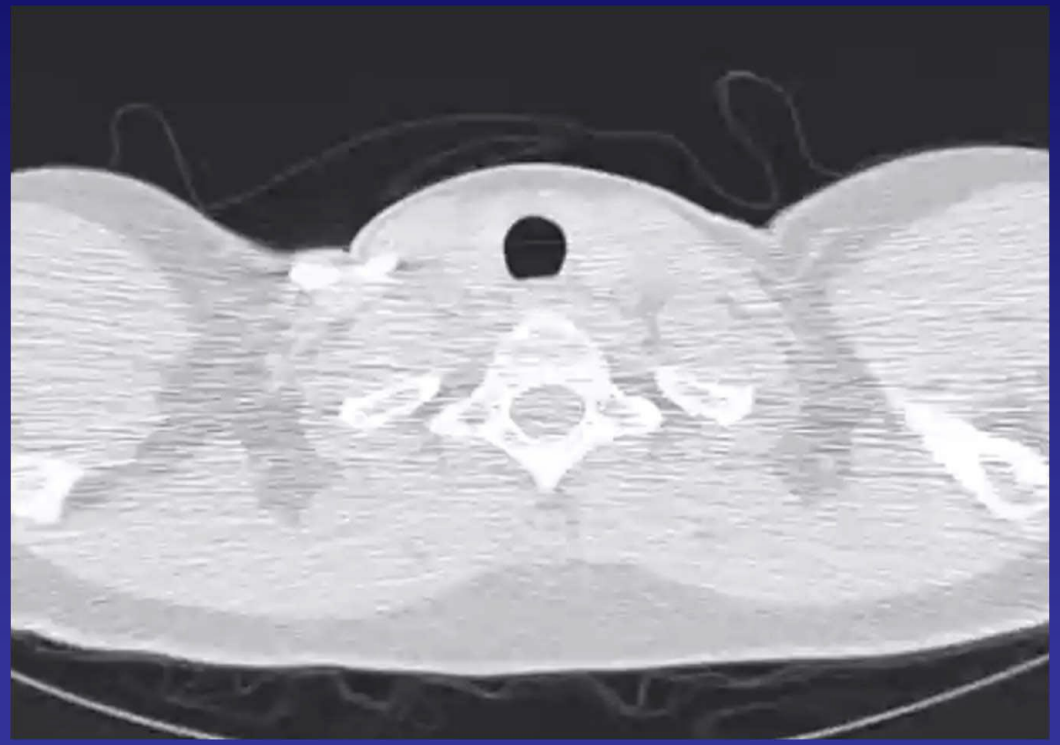
History of peripheral sarcoma

Preoperative CAT scan (1 mm fine cut)

Variable	n
Gender	
Male	18
Female	12
Age (years)	
<40	9
≥41 x <60	14
≥60	7
# of Unilateral Mets by CT (n=53)	
1	19
2	4
3	3
4	4
Tumor Size	
<1cm	25
≥1cm x <2cm	20
≥3cm	8
Tumor Histology	
Osteosarcoma	6
M Fibrous Histiocytoma	5
Leiomyosarcoma	5
Ewing's sarcoma	4
Other	10

Example 1

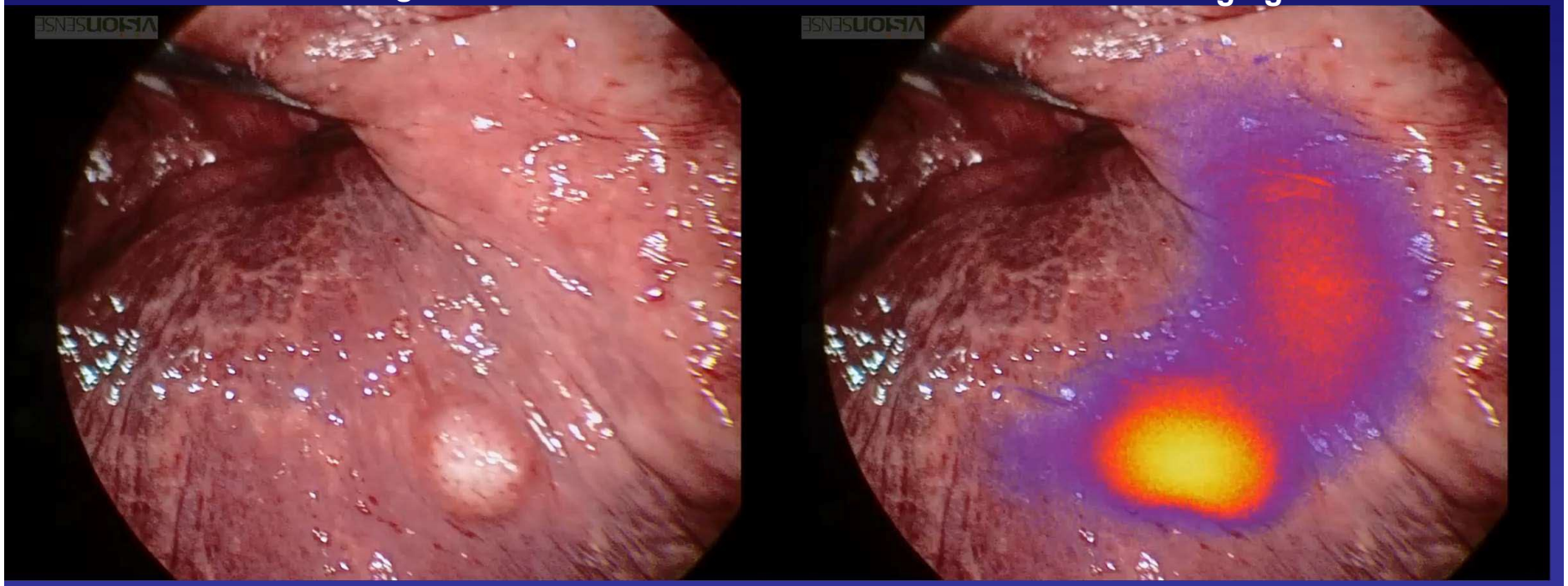
32M, femur osteosarcoma, bilateral mets



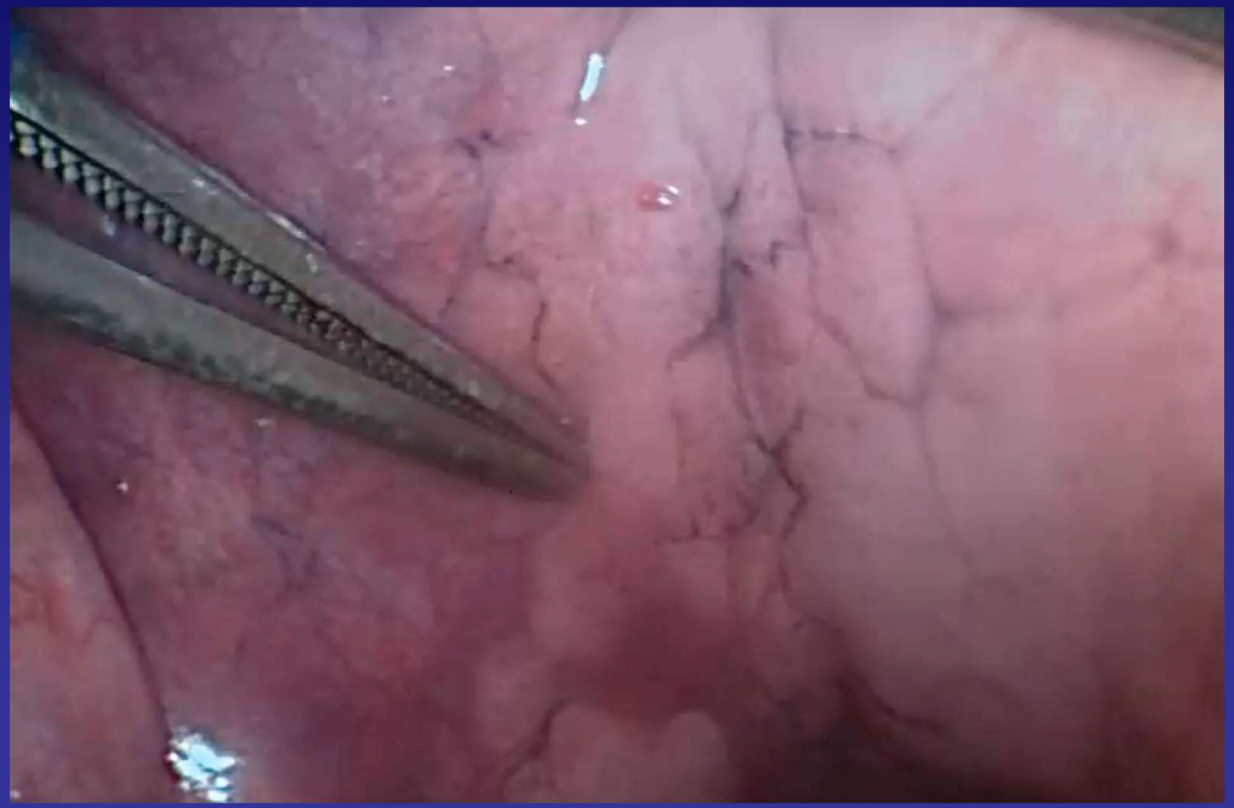
Right Lower Lobe Metastasis

White Light

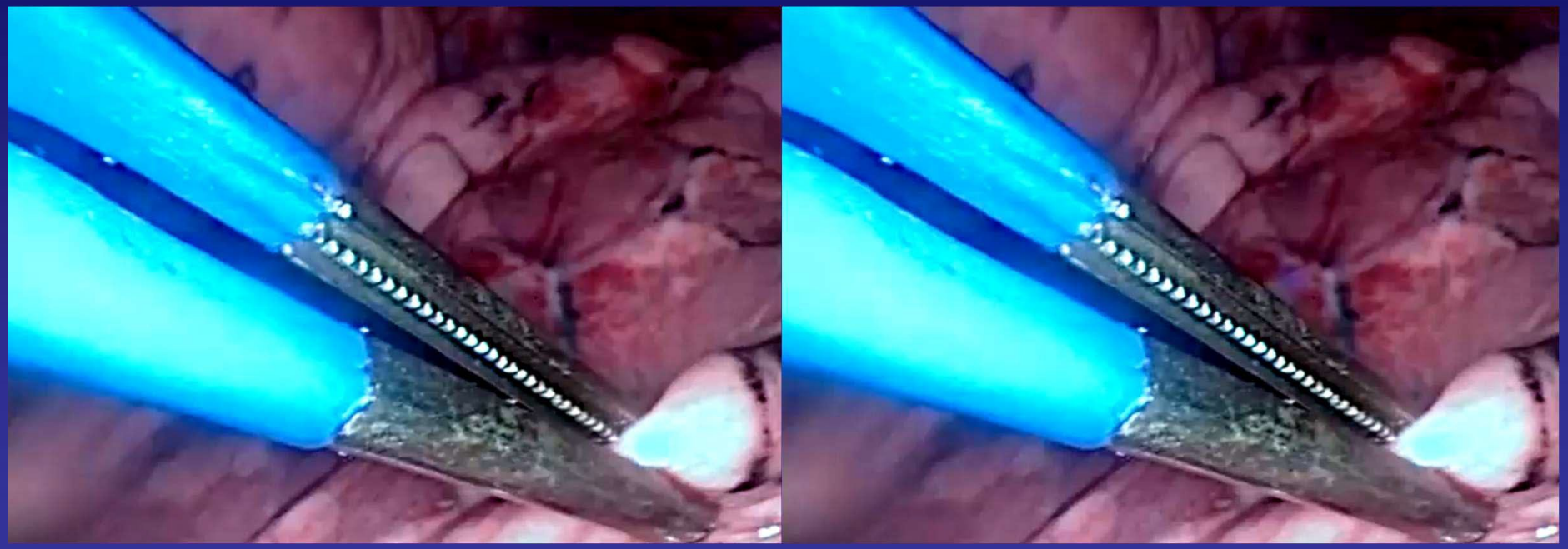
NIR Imaging



Additional lesion? (right middle lobe)

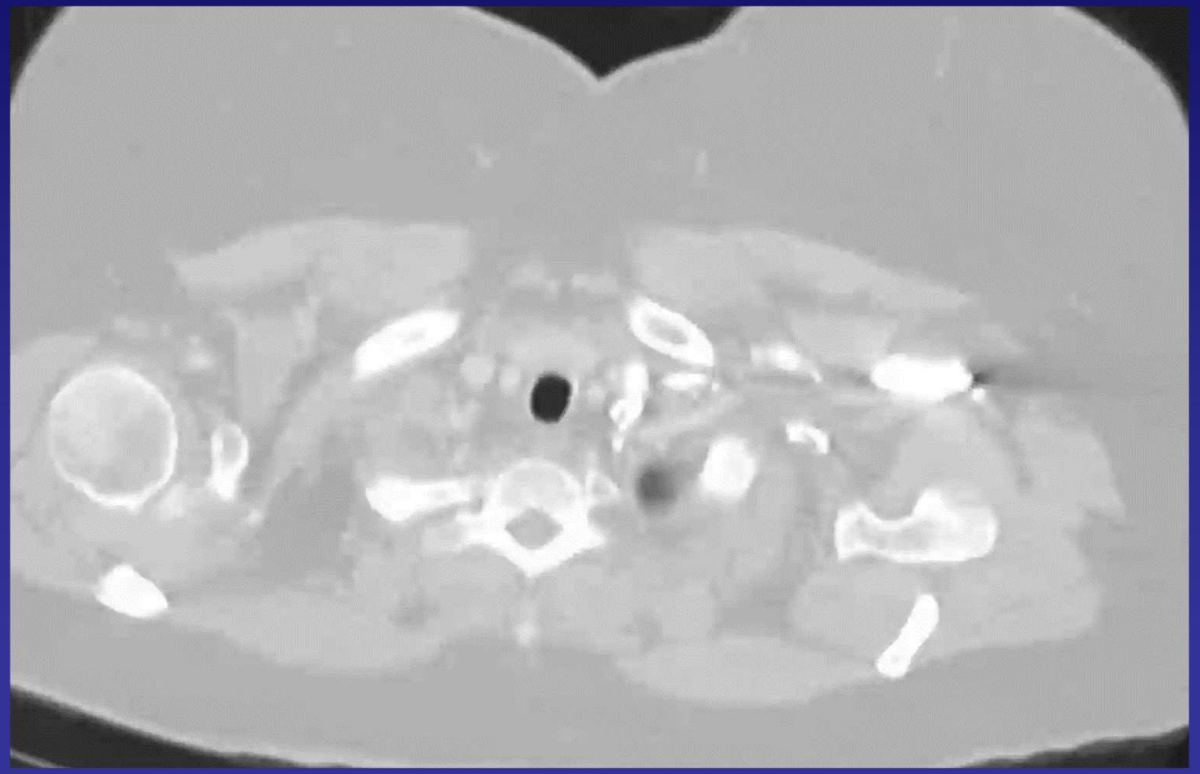


Additional lesion? (right middle lobe)

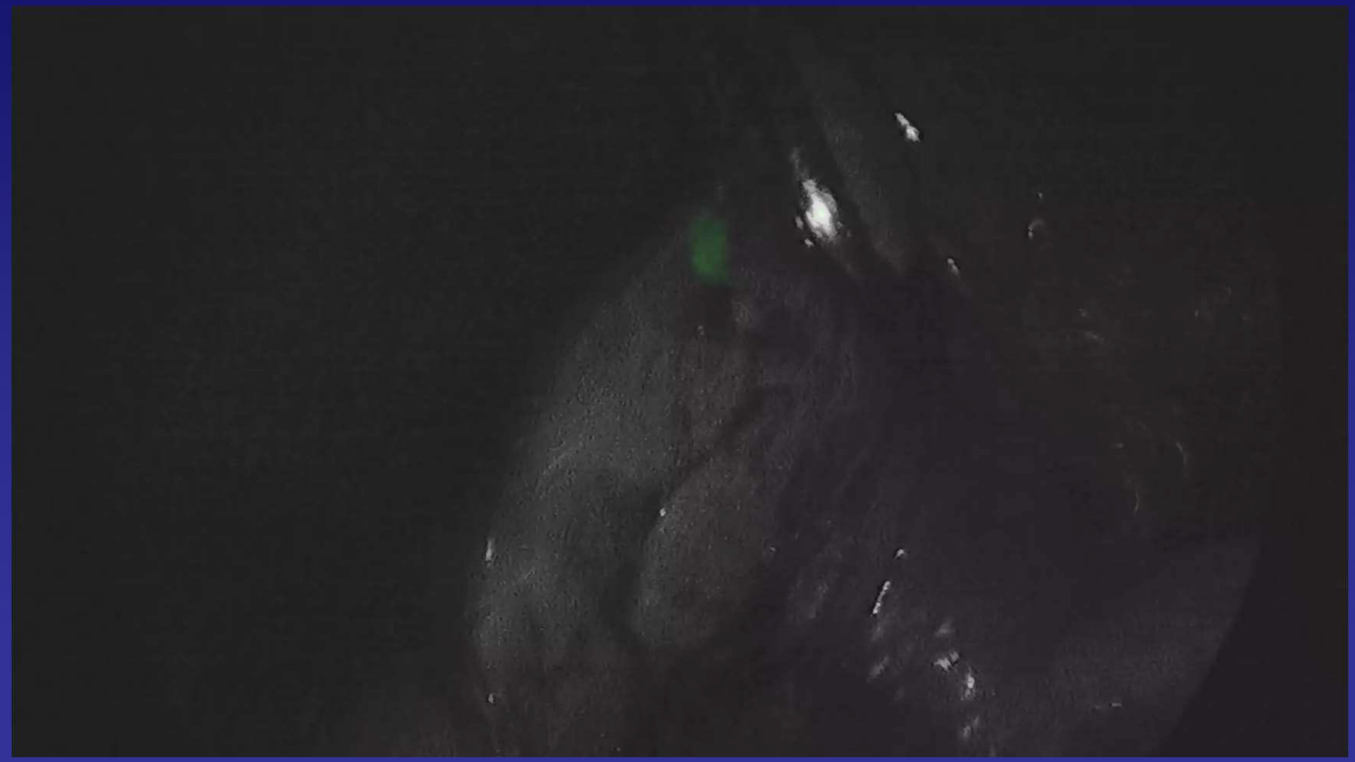


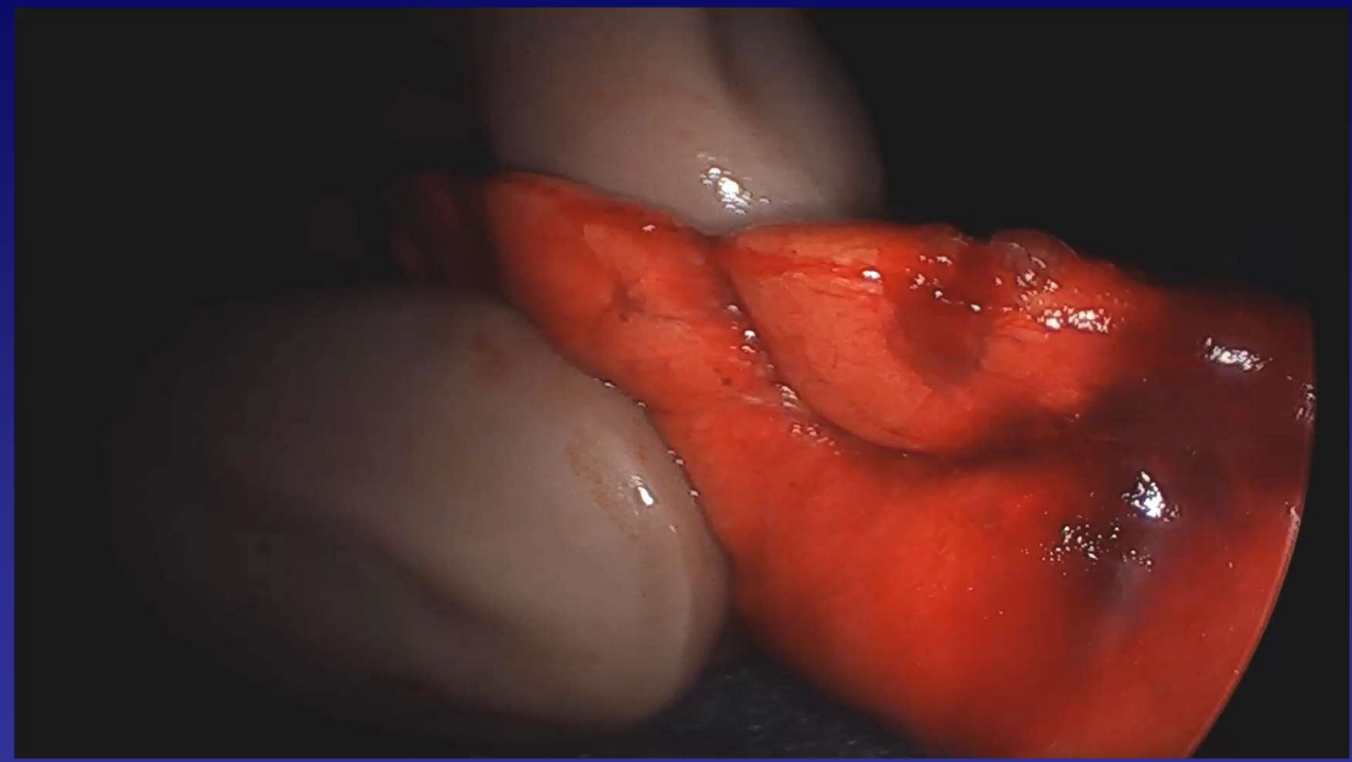
Example 2

39F, leiomyosarcoma, single lingular met

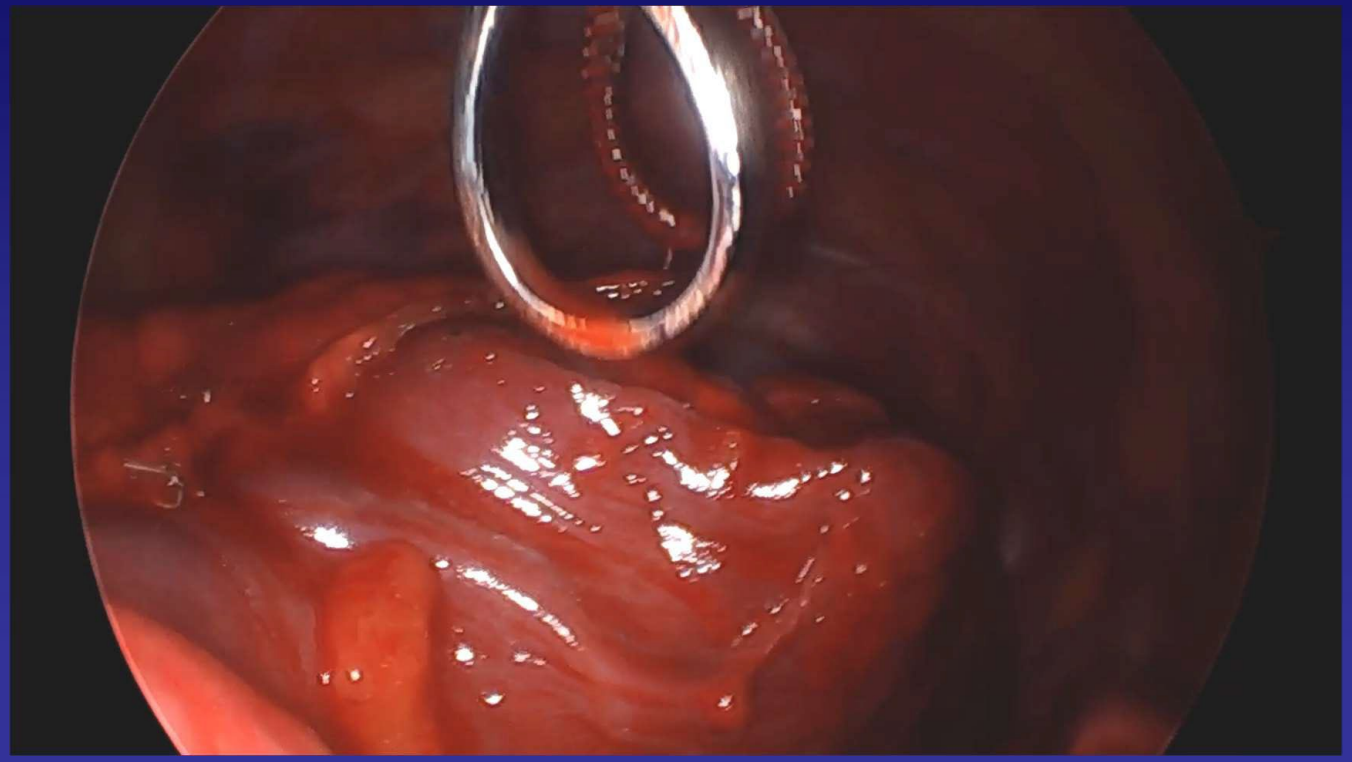


VATS – difficult to locate

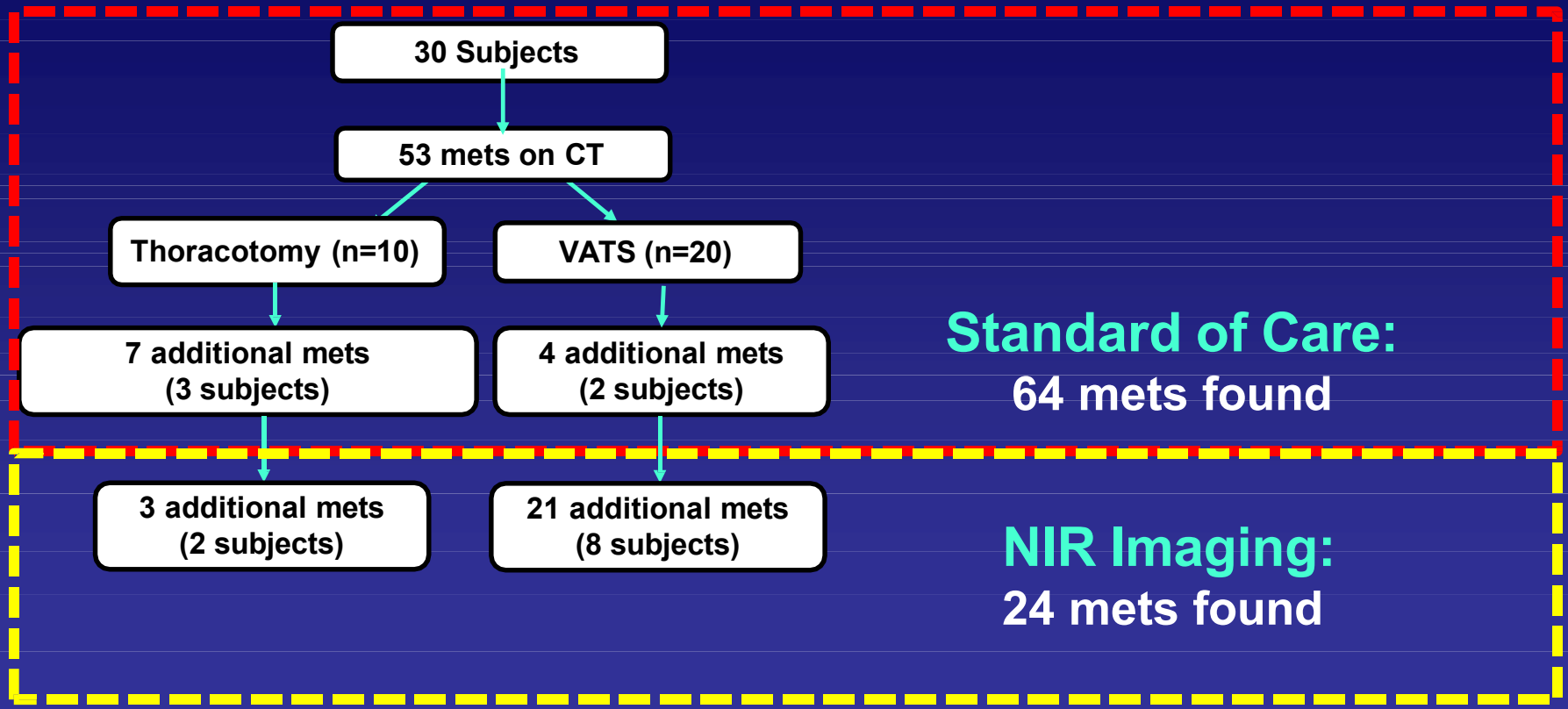




Additional LUL Lesion?

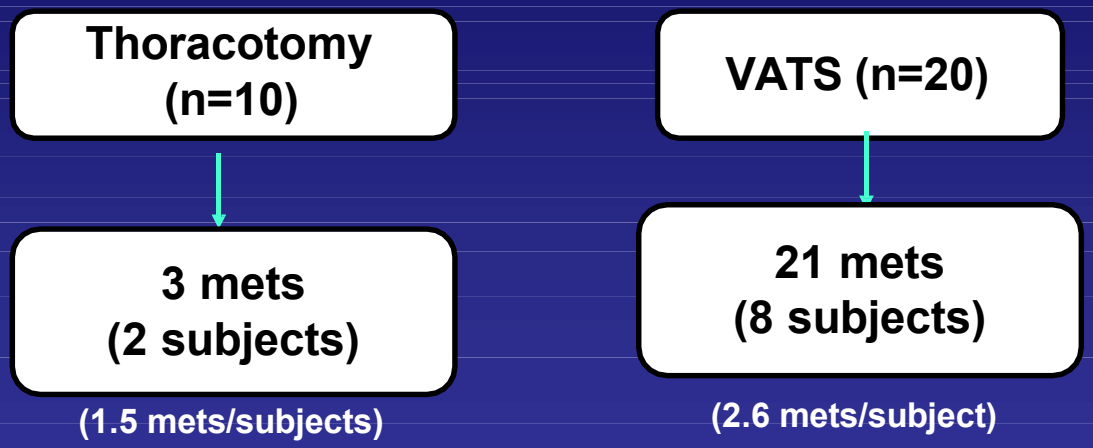


Result #1


30 Subjects
53 mets on CT
Thoracotomy (n=10)
VATS (n=20)
7 additional mets
(3 subjects)
4 additional mets
(2 subjects)
3 additional mets
(2 subjects)
21 additional mets
(8 subjects)
Standard of Care:
64 mets found
NIR Imaging:
24 mets found

Result #2

Thoracotomy versus VATS



Result 3

Does Histology Matter?

Soft Tissue Sarcoma—40 of 44 fluorescent Bone

Sarcomas—36 of 40 fluorescent

Result 4

Primary Limitation

Depth of penetration

Additional Notes

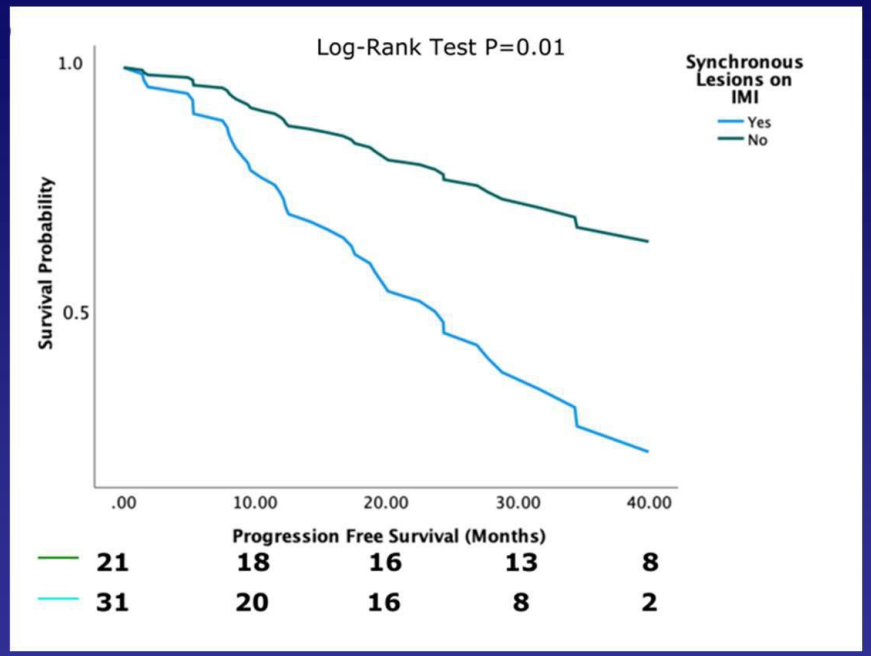
Safe: no toxicity

Costs: ~$2000 per subject (more data to come) Time: 5-

12 minutes per case

Feasibility: thoracoscopic instruments/monitors Intuitive for surgeons, minimal learning curve

Follow up data: Improved 5-year survival!!

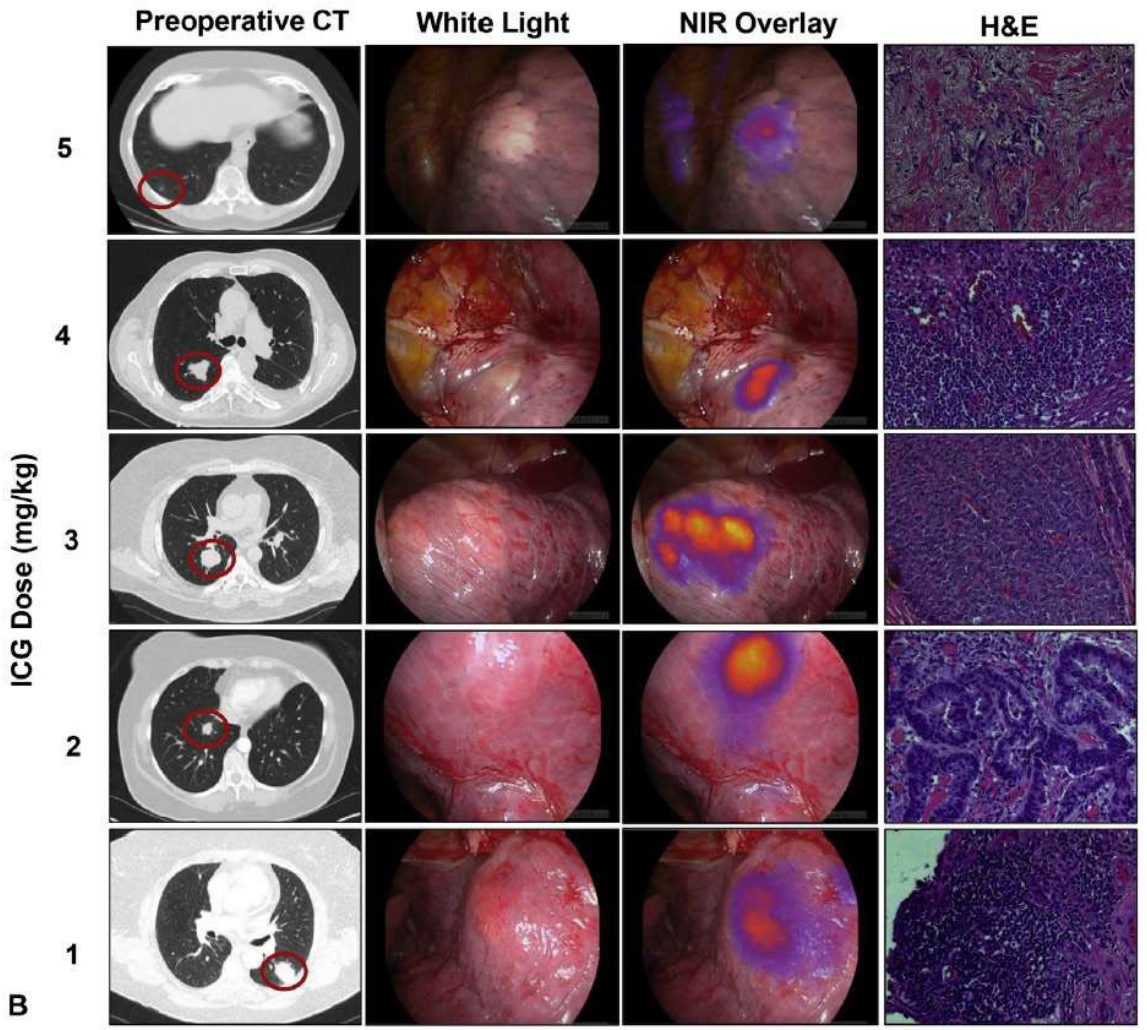


Impact of Intraoperative Molecular Imaging after Fluorescent-Guided Pulmonary Metastasectomy for Sarcoma

Feredun Azari MD, Gregory T Kennedy, MD, Kevin Zhang, BA, Elizabeth Bernstein, BA, Robert G Maki, MD, PhD, Colleen Gaughan, MD, Doraid Jarrar, MD, FACS, Taine Pechet, MD, FACS, John Kucharczuk, MD, FACS, Sunil Singhal, MD, FACS

(J Am Coll Surg 2022;234:748–758.

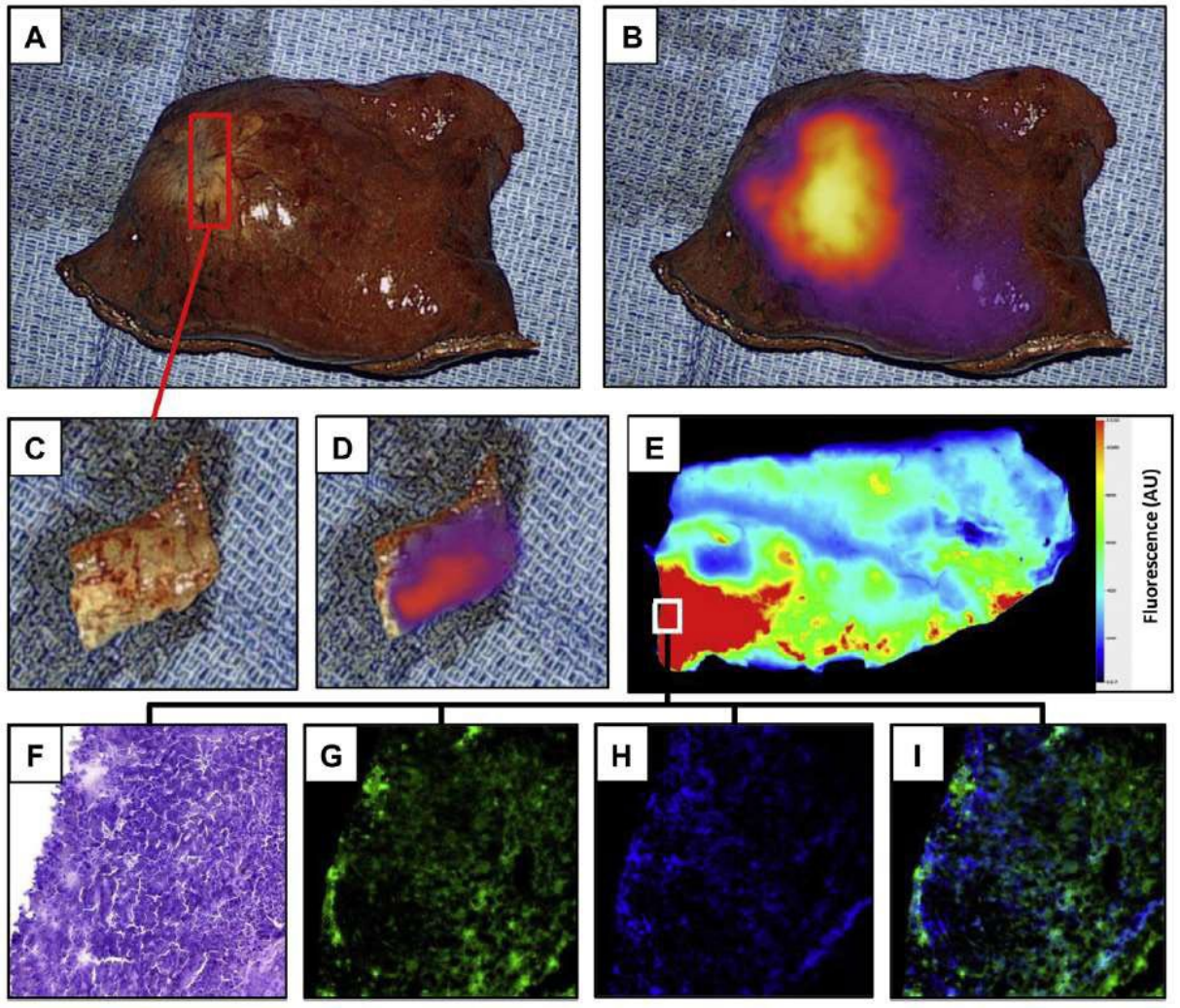
Pulmonary metastasectomy: any sarcoma or colorectal cancer



Optimization of Second Window Indocyanine Green for Intraoperative Near-Infrared Imaging of Thoracic Malignancy

Andrew D Newton, MD, Jarrod D Predina, MD, Christopher J Corbett, BA, Lydia G Frenzel-Sulyok, BA, Leilei Xia, MD, E James Petersson, PhD, Andrew Tsourkas, PhD, Shuming Nie, PhD, Edward J Delikatny, PhD, Sunil Singhal, MD, FACS

Dosing matters though 5 mg/kg works every time.



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Preoperative therapies may matter but need more patients to test this.

Conclusions

- NIR Imaging identifies additional metastases
- Particularly helpful during minimally invasive surgery
- What is happening based on follow up data?
  - If a patient with a suspected solitary lung met is discovered to have additional lesions, they are started on chemotherapy and immunotherapy.
- Our goal is to provide a DIAGNOSTIC test (not a therapeutic application) that can help medical oncologist decide what to do.

Future Directions

Multi-institutional clinical trial

- Key principles to remember:
  - This is a DIAGNOSTIC test, not a therapeutic test
  - Current available diagnostic data is only CT scans.
  - This would be a new DIAGNOSTIC piece of information (similar to what PET scanning does for lung cancer)
  - Our trial will not (and does not want to) look at long term survival outcomes. Why? Institutional treatments different, therapies change all the time.
  - This is histology-independent

Trial Design

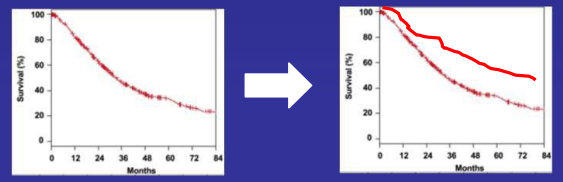
Patient with a solitary pulmonary met (1 mm CT scan)

Intraoperative Molecular Imaging (IMI) with TumorGlow

No additional lesions

Monitor 5 years.
Do these patients do better than patients who we find additional lesions?

HYPOTHESIS:
IMI is a diagnostic test that provides prognostic information for the patient.



Additional lesions

Resectable

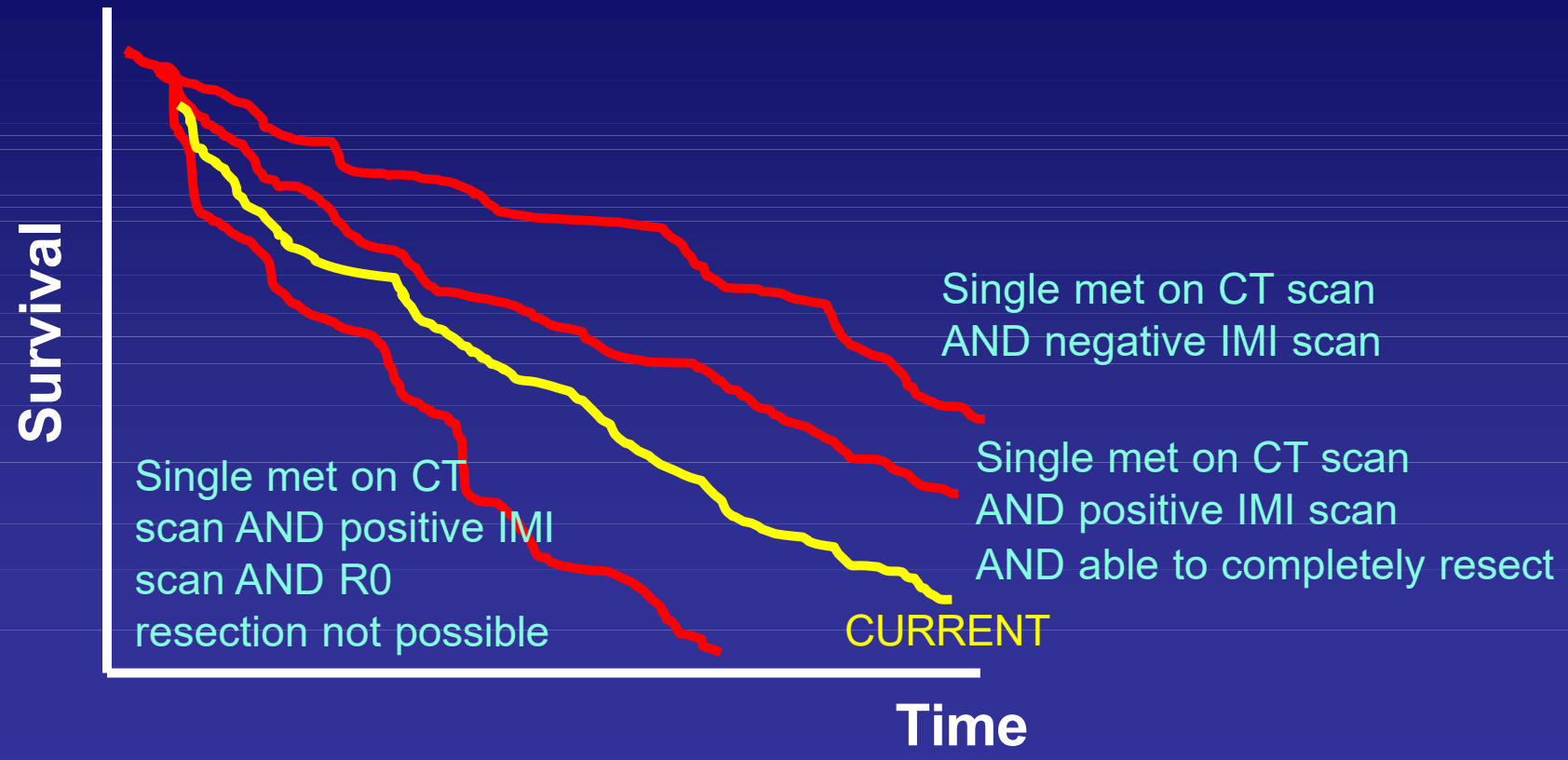
Unable to get disease clearance

Do what multi-disciplinary committee thinks is best next step based on new information

HYPOTHESIS: IMI provides additional information to guide therapy, similar to a PET scan, which may help oncologist decide appropriate next steps.
(** We will not tell oncologist what to do with that data**)

Possible outcomes

IMI may be a new diagnostic test which can help oncologist decide next steps



Other Future Directions

- Camera improvements
  - Software
  - Depth of penetration
- sarcomas – 3 fold brighter dye
- Exploring robotic applications
- Pediatric population
- Larger numbers to look at different histological subtypes

TUMOR GLOW IN PEDIATRICS

Dr. Stephanie Fuller, MD

Children's Hospital of Philadelphia
Center for Childhood Cancer Research

Spence Family
Synovial Sarcoma Foundation

PEDIATRIC TUMOR GLOW

Stephanie Fuller, MD, MS

Thomas L. Spray Endowed Chair of Pediatric Cardiac Surgery
Children's Hospital of Philadelphia
Professor of Clinical Surgery
The Perelman School of Medicine at the University of Pennsylvania

March 1, 2025

WHY A SEPARATE STUDY?

Challenges of Trials in Pediatric Subjects:

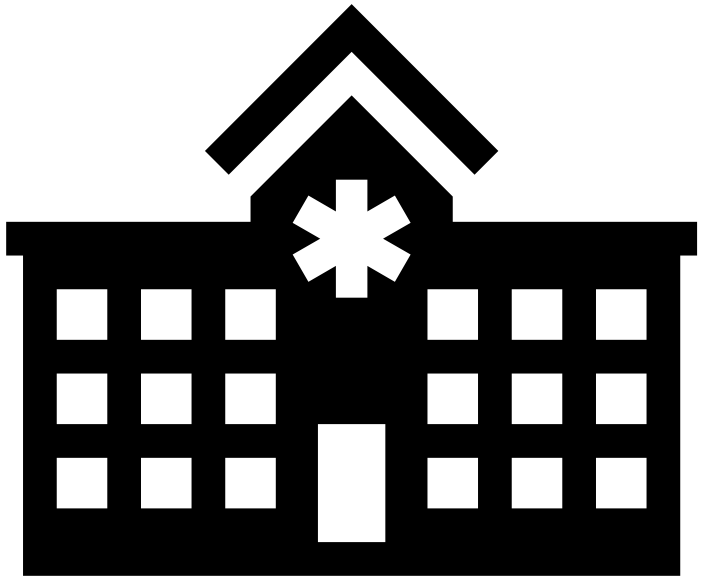
- Children are afforded additional protection when participating in FDA trials
- Risks must be justified by proposed *direct clinical benefit* and heavily scrutinized
- But obviously you must start somewhere, and the first place is to prove no harm
- Caregiver permission and child assent when appropriate (Age 7)

WHY A SEPARATE STUDY?

Challenges of Trials in Pediatric Subjects:

- Pharmaceutical trials present different challenges
  - Cannot assume a drug that is safe in adults is safe in children
  - Heterogeneity in size of patient
  - Pharmacometric considerations
    - Drug absorption and delivery
    - “Off-label” use is no longer available once in a trial because of regulatory processes

WHY A SEPARATE STUDY?



WHY A SEPARATE STUDY?

Location can dictate which patients we treat based on age of patient:

- Free standing pediatric hospital: <21
- Adult hospital: >18
- Combined facility: any age but restricted practitioners

WHY A SEPARATE STUDY?

Practitioner expertise is variable:

- Pediatric surgeons have broad training but not sub-specialized
- Most congenital cardiac surgeons do not perform thoracic surgery
- Many specialized services are not available at a pediatric hospital
- Renders complex coordinated care challenging in children

UNIQUE CENTERS OFFER COMPREHENSIVE SERVICES…. BUT….

How do we get more centers to offer state of the art comprehensive and advanced care?

Clinical Trials and Collaborative Learning

BENCHWORK TO BEDSIDE

STUDY PROTOCOL OBJECTIVE:

1. TO ASSESS THE SAFETY AND TOLERATBILITY OF IV INFUSION OF A SINGLE DOSE OF 5 MG/KG OF ICG.

2. TO ASSESS THE SAFETY AND TOLERATBILITY OF USING HIGH DOSE (5MG/KG) ICG USED WITH NEAR INFRARED (NIR) FLURESCENT IMAGING WHEN USED WITH ICG IN SUBJECTS UNDERGOING PULMONARY METASTASTECTOMY.

STUDY PROTOCOL

Are there any benefits to taking part in this study?

The purpose of this study is not to investigate a possible benefit to you. We do not know whether these video images truly identify cancerous tissue, so you should not expect to get any benefit from being part of this study. You may or may not benefit if the study agent is able to detect cancer that is not visible on the CAT or PET scan or during their standard operation, given the possibility of false identification of cancer tissue.

However, there is a chance that because of the video images your surgeon will remove additional cancerous tissue that they would not have removed during a standard operation. In addition, your participation may make it possible for future patients diagnosed with tumors to benefit from the information that we collect during your participation.

STUDY PROTOCOL

Methodology:	Subjects will undergo infusion of 5 mg/kg indocyanine green, ICG ("TumorGlow") intravenously the day prior to surgery. Then, during the surgical procedure the next day, the subjects will undergo standard-of-care surgery. During the surgery, the fluorescence from the tumor will be used to localize lesions and ensure the entire tumor has been removed, as well as locate any un-expected tumors. The goal of this protocol is to evaluate safety and collect initial efficacy data using indocyanine green with NIR fluorescence imaging in a pediatric patient population undergoing pulmonary metastatectomy.

STUDY PROTOCOL

Inclusion Criteria:

- Male or female children ages 2-18 years
- Primary diagnosis or high suspicion of a solid tumor with metastasis to the lung warranting surgery based on PET/CT or other imaging
- Are scheduled to undergo surgery for suspected metastasis
- Females of childbearing potential agree to use of an acceptable form of contraception from the time of signing informed consent to 30 days after study completion

STUDY PROTOCOL

Exclusion Criteria:

- Any medical condition that can jeopardize safety of the patient
- History of anaphylactic reaction to ICG
- Positive serum pregnancy test
- Impaired liver function
- Receiving another investigational agent within 30 days
- History of uncontrolled hypertension
- Known sensitivity to fluorescent light
- Presence of any challenges hampering compliance with study protocol or follow up

STUDY PROTOCOL

Follow up Period:
28 ±10 *days*

Study Procedure	Visit 1	Visit 2		Visit 3	Visit 4
	Screening (Up to Day -60)	Visit 2a Day of Infusion (Day 0)	Visit 2b Day of Surgery (Day 1)	Follow-up (Day 4 ± 3)	Follow-up (Day 28 ± 10)[1]
Informed consent / assent	x				
Inclusion/exclusion criteria met	x				
Established diagnosis or high clinical suspicion of lung nodules by CT or PET	x				
Clinical chemistry	x				
CBC with differential	x				
Pregnancy test	x	x			
Medical history	x				
Vital signs	x	x		x	
Patient weight	x				
Physical examination	x		x		
12-lead ECG	x				
Study drug administration		x			
Surgery with associated procedures including intraoperative imaging			x		
Investigator Post-Surgery questionnaire			x		
AE assessments		x	x	x	x
ADE assessments			x		
Concomitant medications Review	x	x	x	x	x

STUDY PROTOCOL

Timeline:

FDA Approval: 1 month
CHOP IRB Review and Approval: 2-3 months
Contract with UPENN for ICG: 2 months

CONCLUSION

We want to prove this technique is safe and effective in children to potentially enable its widespread use and adoption.

Next step will be to determine efficacy – does it work in children to improve the local control and effective metastectomy to delay recurrence and progression of disease?

Continue to collaborate with other institutions to share experiences and knowledge.

CONCLUSION

Thank you to the Spence Family and all families who are participating in our registry. Thanks to our colleagues who are advancing science.

Vulnerable time for science and research…..

These contributions whether financial, volunteer or awareness are more meaningful than ever.

MOVING FORWARD:
THE IMPACT OF PATIENT REGISTRIES & BASIC SCIENCE

Rachel Hurley, MD PhD

Children's Hospital of Philadelphia
Center for Childhood Cancer Research

Spence Family Synovial Sarcoma Foundation

SYNOVIAL SARCOMA REGISTRY AND BIOSPECIMEN REPOSITORY (SSRBR)

Established for **all patients** treated with **synovial sarcoma** in the United States to collect clinical information and serve as a biospecimen repository

AIMS OF THE SSRBR

- Characterize the patient population within the registry
- Create a central database of clinical information, imaging results, and genomic data
- Generate a biospecimen repository
- Advance clinical and translational research in synovial sarcoma

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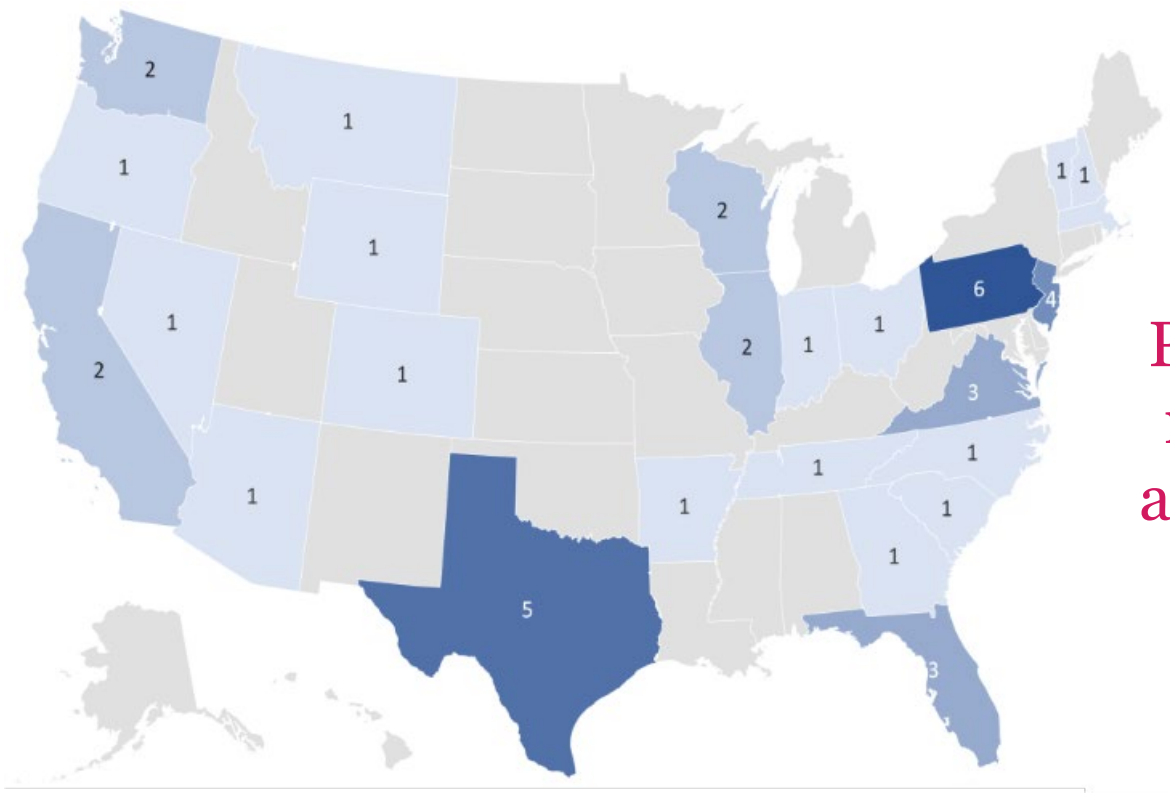
REGISTRY ENROLLMENT



Patient population has received medical care across at least 25 states and the District of Columbia.

Registry established June 2023;
Data cut-off of April 1, 2024

PATIENT DEMOGRAPHICS

Table 1. Patient Demographics		SSRBR Participants *N* = 46 (%)
Sex		
	Female	29 (63.0)
	Male	17 (37.0)
Race		
	White	41 (89.1)
	Asian	2 (4.3)
	Black or African American	1 (2.2)
	Other	1 (2.2)
	Multiple	1 (2.2)
Ethnicity		
	Non-Hispanic or Latino	38 (82.6)
	Hispanic or Latino	6 (13.0)
	Unknown	2 (4.3)
Age at Diagnosis		
	0-9	2 (4.3)
	10-17	11 (23.9)
	≥18	33 (71.7)

PATIENT DEMOGRAPHICS

Table 1. Patient Demographics	SSRBR Participants *N* = 46 (%)
Location of Primary Tumor	
Head/Neck	5 (10.9)
Chest/Back	12 (26.1)
Abdominal/Pelvis/Retroperitoneal	5 (10.9)
Upper Extremity	4 (8.7)
Lower Extremity	19 (41.3)
Unknown	1 (2.2)
Regional Lymph Node Involvement at Diagnosis	
Yes	0 (0)
No	41 (89.1)
Unknown	5 (10.9)
Metastatic Disease at Diagnosis	
Yes	6 (13.0)
No	40 (87.0)
Maximum Diameter of Primary Tumor (cm)	
≤5	10 (21.7)
>5	33 (71.7)
Unknown	3 (6.5)

PATIENT RESPONSES WITHIN THE REGISTRY

- **5-Year Overall Survival**:
  - 81.5% for patients with non-metastatic disease
  - 50% for patients with metastatic disease

- **Median Follow-Up**:
  - 2.58 years for patients with non-metastatic disease
  - 3.24 years for patients with metastatic disease

NEXT STEPS:
Describing the Patient Experience in Relapse

Patients with Recurrence	N = 28
# of Recurrences (avg)	3.68
Surgery	**19**
Local	8
Lung	17
Other	3
Radiation	**17**
Local	7
Lung	13
Unknown/Other	4
Chemotherapy	**21**
Trabectedin	2
Pazopanib	13
Continuous Infusion Ifosfamide	5
Clinical Trial	10
AIM	4
Regorafinib	2
Oral etoposide	1
Temozolomide	1
Liposomal doxorubicin	1
Olaratumab	1
Gemcitabine + docetaxel	2
Ifosfamide (not continuous)	1
KI (unspecified)	1
High Dose Ifosfamide	1
Dacarbazine (DTIC)	1
Trabectedin + Doxil	1
Other	**3**
Ablation	2
Pulsed Electric Fields	3

AIMS OF THE SSRBR

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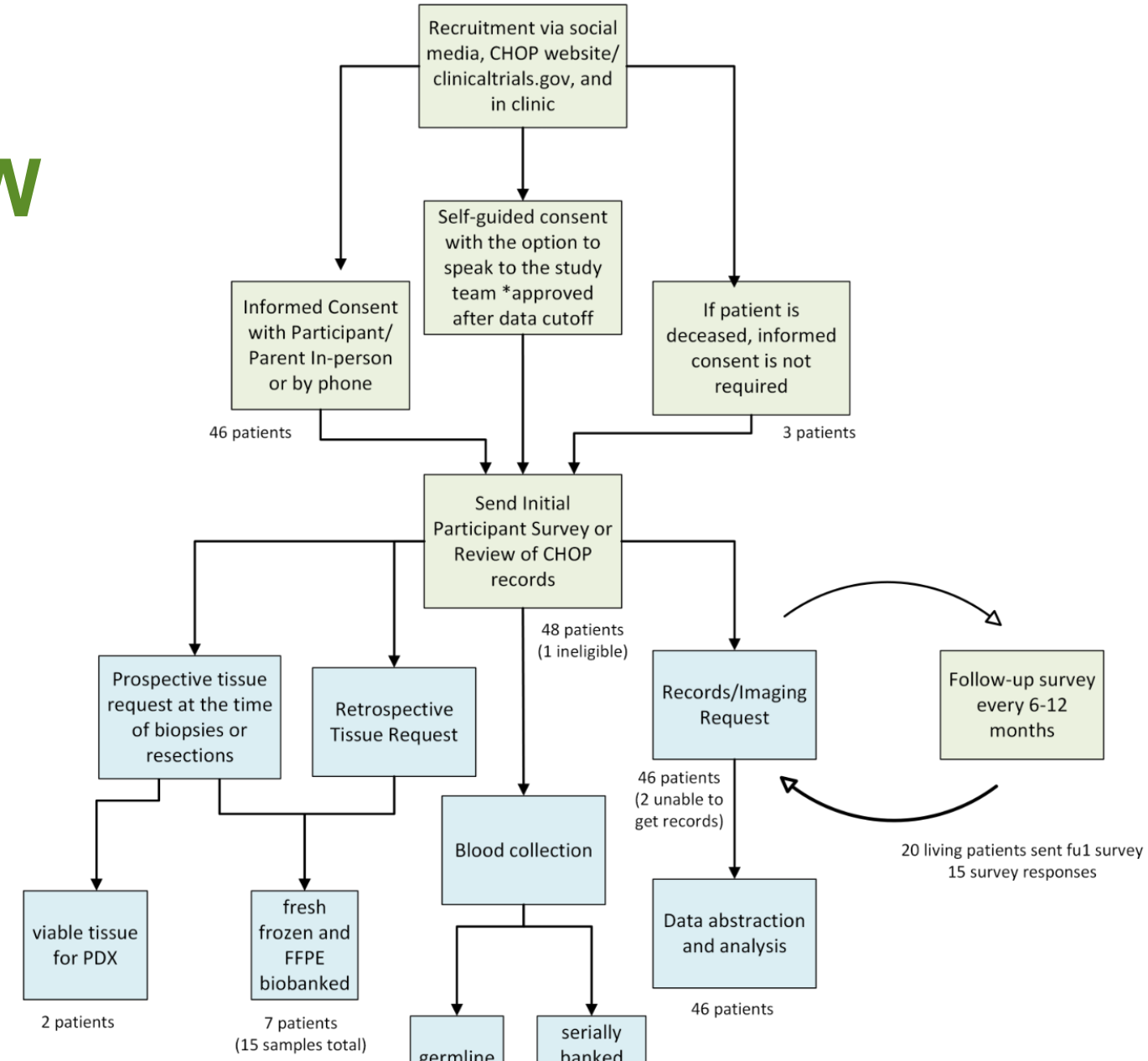
- Generate a biospecimen repository
- Advance clinical and translational research in synovial sarcoma

REGISTRY WORKFLOW



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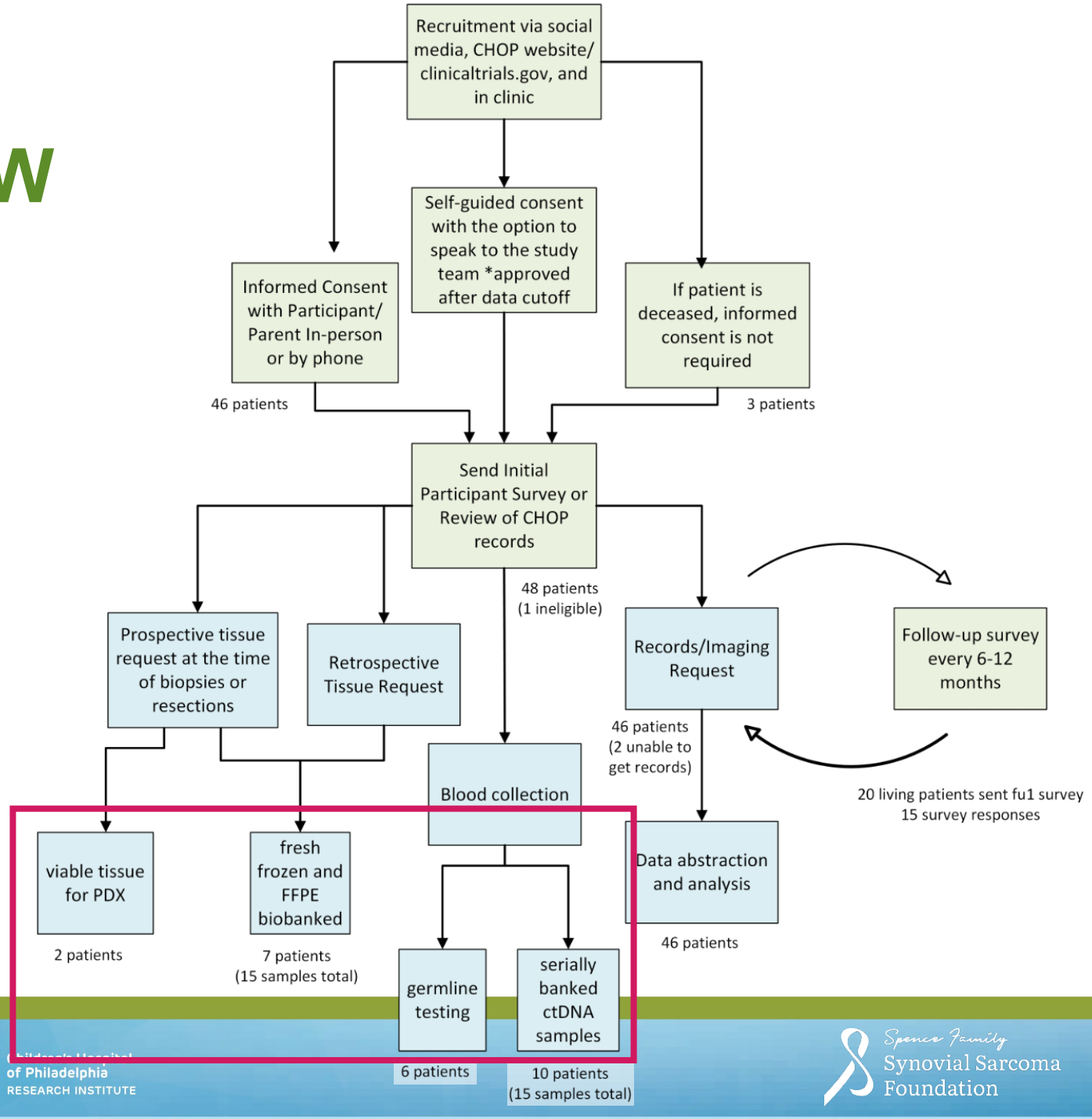

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- Li Zhai

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- James Robinson
- Wynn Bastianelli
- Karen Huang
- Jacquelyn Crane

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- NIH NHGRI T32
- Marlene Shlomchik Fellowship

Spence Family Synovial Sarcoma Foundation

Q&A

Please submit your question for the presenters via the chat.

Disclaimer:

We cannot provide personalized medical advice during this event.

WANT TO GET INVOLVED?

For Providers:

Synovial Sarcoma Tumor Board

Hosted by the Very Rare Malignant Tumors Program at the Children's Hospital of Philadelphia (CHOP) and Dr. Ted Laetsch.

Takes place virtually from 5-6 PM EST on the 4th Monday of every month.

Open to medical personnel only. Patients and their family members are not permitted to attend.

To request to be added to the email list and calendar invite, please email project manager Lauren Gutstein at **gutsteinl1@chop.edu**.

Children's Hospital of Philadelphia
RESEARCH INSTITUTE

For Patients:

Children's Hospital of Philadelphia

Spence Family Synovial Sarcoma Foundation

Synovial Sarcoma Registry and Biospecimen Repository

*Do you have or know someone diagnosed with **Synovial Sarcoma**?*

We want to better understand and treat it.

You can help.

How it works:

You give permission to access your
- medical records
- leftover tumor tissue
- blood/saliva sample

We use this data to advance research and improve outcomes for patients in the future.

Consent Form

For more information:
Study Website: https://tinyurl.com/synovialsarcomaregistry
SynovialSarcomaRegistry@chop.edu; (267)827-8145
Principal Investigator: Dr. Theodore Laetsch

FINAL REMARKS

Thank You for Attending & Supporting This Conference!

A special thank you to everyone who helped spread the word and make this event possible:

- Spence Family Synovial Sarcoma Foundation
- NJI Media
- Sarcoma Alliance
- Children's Hospital of Philadelphia (CHOP) & PennMedicine

And most importantly, THANK YOU to all the patients and study participants who make this work possible.