



**ACPMP Research Foundation Virtual Symposium: October 2, 2020**  
**LIVE Q&A**

Question	Answer(s)
How many CRS&HIPEC procedures have been done on 1 patient? I am scheduled for my 5 due to multiple reoccurrences since original diagnosis in 2013(LAMN)	Julie, patients can have multiple HIPEC procedures. The factors that determine the number that can be done is determined by the patient, the ability to tolerate chemotherapy but most importantly the surgeon's ability to remove all disease (which becomes harder). In addition, the risks to bowel injury also increase with every future surgery. I don't think there is any limit to the number of procedures that have been done on one patient but most patients will have 1-3 on an average. Good luck!
How are "liquid biopsy" results (i.e. Natera) different than CEA results?	Thank you for the question. CEA is a protein that is often used as a marker for cancer recurrence, and different types of tumors can secrete, or release, CEA. When it is elevated and we know someone has a history of a certain type of cancer, it heightens our suspicion that it may have recurred. Liquid biopsy results look for tumor cells or DNA from tumor cells that may help detect recurrence (potentially earlier), but ongoing studies are helping us better understand the role of integrating this into management.
have we identified the presence of Mesothelin in this type of cancer?	To date, it is unknown whether appendiceal tumors express mesothelin. See more here:  <a href="https://acpmp.org/nci-reaches-out-to-acpmp-for-assistance-with-new-clinical-study/">https://acpmp.org/nci-reaches-out-to-acpmp-for-assistance-with-new-clinical-study/</a>
Will we be able to acquire the decks from the speakers (all or some) to be able to share with our own local oncologist? How can we best share/promote for sake of self-advocacy AND further promote these efforts within our own local communities?	The entire program is being recorded, and videos will be available on the ACPMP website and YouTube page. We will break up the videos by presentation so you will be able to share links of each presentation as needed.
How long has HIPEC been an established surgical treatment for appendix cancer? Earlier slides showed prognosis scale to ~16 years. Is this because HIPEC is only that old? Or is ~16 years the best documented prognosis?	Dr. Sugarbaker began performing CRS/HIPEC in the 1980s. He and other centers have data going back longer than 16 years. Here is a good paper on the history of HIPEC:  <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4754315/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4754315/</a>
Thanks to Dr. Levine's skills and the other staff at Wake Forest, I am a 12 year survivor with a high quality of life.	Congratulations James!  Congratulations and thank you for the kind words. I am honored to have been able to help!



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<p>Can you please discuss why EPIC isn't more widely available as a treatment alternative, especially for patients who are having a recurrence after having CRS and HIPEC? Also Dr. Levine mentioned there are pluses and minuses to EPIC, can you please expand on those?</p>	<p>There is currently no data to show that EPIC offers any significant survival benefit but there is data to show that it does increase the risk of complications after surgery. For these reasons, most HIPEC surgeons have not adopted it into their practice. There is a clinical trial going on at the Memorial Sloan Kettering Cancer Center in NYC comparing HIPEC to EPIC. The findings of that study will be important and may change how we do things.</p>
<p>A heartfelt thank you for all the information, opinions and treatment options.</p>	<p>You are welcome, thank you for attending!</p>
<p>Re: iterative, laproscopic HIPEC. Did Dr. Eng say this is done every 6 weeks? Earlier question said traditional HIPEC can be done, on average, 1-3 times. What is the thinking about iterative?</p>	<p>We do this every 6 weeks, with systemic chemotherapy in between. This to get maximum local effect with minimal systemic side effects</p>
<p>Dr Turaga. Can a patient have lapro hipec after Cyto surgery if appealing to treatment?</p>	<p>yes, absolutely</p>
<p>I have several questions starting back to the beginning of having my appendix removed. Back in 2019 February. As an emergency at a local hospital and the slid diagnose having different opinion of findings between my local hospital and Huntsman in Utah. As an educated individual I find exact communication and findings lacking. Now with covid and travel distance HOW as a patient can I be my best advocate for treatment and communication?</p>	<p>I recommend the following</p> <ol style="list-style-type: none"> <li>1. Keep a file for all your records, read all your reports and request notes</li> <li>2. Use support groups like ACPMP</li> <li>3. Utilize virtual second visits, remote second opinions.</li> </ol> <p>I think remote technologies can be utilized effectively to connect with physicians</p> <p>Hi Desiree, I want to add that this Q&amp;A is not intended for personal consultation and we encourage patients to connect with their oncologist's directly. Thank you!</p>



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<p>How does the liquid biopsy compare to standard tumor markers? Just more specificity?</p>	<p>This is an extremely sensitive test to detect cancer in the blood that can be used to guide chemotherapy, surgical response and follow up. As you know conventional CEA markers don't detect disease very easily</p> <p>Especially as some tumors don't secrete CEA for example, standard tumor markers are not always reliable (just because it isn't elevated doesn't mean it's not there). Liquid biopsy is evolving and more research needs to be done, but the potential is for better and earlier detection.</p>
<p>Can you have lapro HIPEC if you have already had an open HIPEC procedure (I had mine Jan 2016) Is lapro</p>	<p>Yes, it is absolutely possible</p>
<p>What are the recommended genetic tests for people with LAMN/PMP who have been previously treated with CRS and HIPEC? What companies are experienced in this testing?</p>	<p>It depends on what you mean by genetic test. If you are talking about genetic testing to determine if your cancer was caused by an inheritable, germline mutation that may run in your family, we do not routinely recommend that type of testing for appendiceal cancer unless there are other reasons - other cancers that run in your family or multiple members of your family with appendiceal cancer. If you are asking about testing the tumor itself to see what the mutations are and whether any of them may be used for treatment, there are a number of companies that provide what is called next generation sequencing to look at the gene expression profile. Also, a number of academic medical centers offer their own NGS testing. Your medical or surgical oncologist may have one that they prefer.</p>
<p>Since KRAS and GNAS are frequently mutated in PMP patients, are pharmacological approaches that repress the overstimulated signaling pathways a promising therapeutic approach? Can these approaches specifically reduce mucin?</p>	<p>Currently there are no pharmacological approaches to suppressing the mucin secreting pathways. However, there is research ongoing looking at the use of MAP Kinase inhibitors of which KRAS is a part. Just recently has it been suggested that GNAS may play a role in mucin secretion, so hopefully this will become a potential target someday.</p>
<p>Can you explain the difference between Goblet Cell Carcinoma &amp; Ex-Goblet Cell? This is a question that gets asked/discussed amongst the GCC members of the ACPMP FB group and is confusing for most. Is it simply the difference in the grade as depicted on one of Dr. Turaga's slides? Thank you.</p>	<p>This is a good question. The new pathological guidelines think of tumors as goblet cell carcinoid (which is very well behaved, and curable) to goblet cell carcinoma/ex-goblet adenocarcinoma, which is much more aggressive and spreads rapidly to the peritoneum. Goblet cell carcinoma and ex-goblet are identical in most regards, just different terminology.</p>



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<p>Dr. Levine mentioned sleep disorders were common after CRS and HIPEC. Can you give us more detail about how this manifests? Is this a common long term problem?</p>	<p>This is a common and sometimes lasting issue for our patients. The management can be complex, however, good sleep hygiene is always the first step. That refers to a very quiet room, minimizing naps during the day, avoidance of screen images for &gt;30 minutes prior to sleep, and similar measures. While sometimes medication can be helpful, I would certainly start with these simpler measures.</p>
<p>What are the most recent thoughts on prophylactic HIPEC (PIPAC) for signet ring cell. In my case: T4B, N2, M1a, Tang B disease. PCI = 0 post cytoreduction. There doesn't seem to be a consensus on this prophylactic approach, so I seem to just be waiting for recurrence with this aggressive disease. Thank you!</p>	<p>No data to suggest that it works. I would not recommend it. Liquid biopsy technology might help detect any residual disease or recurrence but benefit unproven.</p> <p>I believe there was a recent study out of Australia which didn't demonstrate any survival benefit for prophylactic HIPEC in appendix cancers, and the data from recent large-scale colorectal cancer trials didn't demonstrate a survival benefit either. Given the risk of recurrence sometimes we do discuss a second-look laparoscopy alone any time from 6-12 months after surgery, but not prophylactic HIPEC.</p>
<p>I am 69 y old and have had CRH/HIPEC twice (20 and 10 y ago - DPAM grade). I have now a growing (9x5 cm) recurrence on the abdominal wall just above liver (CEA rising from 5 to 65 in the last 5 years). Should I consider Prof Morris novel bromelain/acetylcystine treatment a good alternative for a third "aggressive" surgery, in order to give me another 10y of free disease ?</p>	<p>This is best discussed with the trial coordinator and your medical team.</p> <p>We are actively working on using Bromelain as part of a clinical trial in collaboration with Dr. Morris. The study is not yet open and is awaiting approval from the FDA and the Australian authorities.</p> <p>The medication is only available in this country with emergency FDA approval and only a single patient has been treated in the U.S.. Hopefully, we will be able to offer you participation in the trial soon.</p> <p>Dr. Levine</p>
<p>To Radiology: What are the current thoughts on PET scan surveillance for signet ring cell appendiceal adenocarcinoma that never shows up on tumor markers, and ctDNA is negative? I am currently only getting CT scans which are negative, but are they truly so, that is the question?</p>	<p>I will let the radiologists answer but the following thoughts</p> <p>1. Mucin does not light up on PET scans, contrast (regular IV used in CT scans) is sometimes better. High grade signet ring cancers may show up, but unfortunately we miss a lot of cancers on PET scans but also on CT and MRI. I prefer CT/MRI for surveillance in addition to tumor markers. We also keep low thresholds for laparoscopy.</p>
<p>I am 74 and had CRS/HIPEC 10 years ago. I had a CT scan 3 years ago with no evidence of reoccurrence. How frequently should I have follow-up CT scans?</p>	<p>Great news!!! Best discussed with your treating team.</p>



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How accurate are CT scans in showing neuroendocrine tumors?	CT scans are sensitive in detecting abdominal masses, but the best radiographic imaging now for neuroendocrine tumors is a PET-Dotatate scan.
Will the registry include data on fertility after treatment and if patients are able to have children in the future?	Yes, at a minimum, there are questions in the Treatment module that are relevant to this area of inquiry.
is the patient registry international or restricted to the US?	The patient registry will be international, patients from any country may participate.  Thank you for this question. It is international!
How common is it to find another unrelated cancer like cancer of the bile duct during appendiceal cancer treatment?	Great question. I don't think we really know, given how rare appendix cancers are and no definitively known associated inherited syndrome.
How relevant is a rising CA 125 to probability of recurrence?	CA 125 is one of the tumor markers that we routinely follow for recurrence of appendiceal cancer. Although it is not 100% specific, and can be elevated for other reasons (other causes of irritation of the peritoneum), in the right setting, it would certainly be concerning for a recurrence and may suggest a need for additional or different testing to be sure.
Thanks to all the amazing presenters, fantastic learning opportunity, so comprehensive and encouraging	You are welcome, thank you for attending!
Have you encountered LMAN that has metastasized to inside the lungs? How can this happen? I am 10 years out, last hipec in 2017 and nodules were discovered in 2019. I now have 4 nodules, 2 were resected last month, the other 4 are under 1 cm.	The pathology should be reviewed again carefully
Thank you to Dr. Turaga and Dr. Eng for your replies. To both of you, and the entire symposium panel, it is simply invaluable to be able to join internationally and ask questions to this prestigious panel. Thank you! Thank you!	You are welcome, thank you so much for attending!



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One would think the rarity would lead to better research outcomes and make us a desired research cohort	agree
While working with specialist is critical in these cases...how do you recommend working with local teams for ongoing monitoring post-surgery? Do we connect our local medical oncologist/GP with outside teams for joint care? Is that more of an insurance dilemma? (not wanting to pay for double consults?) How can that work or any suggestions welcome.	Most of us are used to working with local teams. You need to help establish the connection and persist in making sure that the lines of communications are open.
is there a geographical map of all that have been diagnosed with PMP throughout the world or US?	I don't believe this currently exists. However, this data will be captured in the ACPMP patient registry.
Can low grade turn into high grade over a period of several recurrences?	there have been cases reported where transformation of tumors have occurred.
If you needed to get a fresh tumor tissue for molecular sequencing (my last was during surgery in 2013) is it worth while to obtaining by lapro to best get a representative sample (familiar that it is difficult to get good sample by biopsy)	fresh tissue is certainly better if safely possible.
I have an MSH3 mutation. I haven't heard that mentioned today. Is this unusual? Better to have? Worse to have?	unknown currently. it is a variant of the MSH mutations but doesn't necessarily predict for immunotherapy.
About clinical trials—most are not available to children. What is the current landscape for finding trials for patients <18 years old?	Childrens oncology group is a good resource. also trials.gov
Thank you all so much for providing this forum for educational information for the patient and the caregiver. ACPMP, I am so grateful for your organization! What a comfort for so many!	



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What experimental research is being done to cure the disease such as a virus which could target the cancer cells?	There are clinical trials for intraperitoneal virus delivery ongoing.
Dr. Lambert and everyone - Thank you. Wellness and Blessings. from Idhao	
Will a recording of this full webinar be available to watch on your website, for those of us who missed some of it?	Yes, recordings will be available.
Such good information, I really appreciate everyone's time and knowledge to help our community!!	
Thank you all for your time discussing during this event!!	
Thank you all for being here. So helpful	
Thank you for providing us with hope. My father unfortunately passed away within 6 months of HIPEC and CRS last month but this symposium has given me so much hope for all the other patients and we appreciate that you are championing something so rare so that someday we can find a cure for this awful disease!	
Curious: how many attendees were there today? How "not alone" are we? :-)	400 registered, around 200 logged in at a given time!



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Thank you!!!	
Are the individual regional sessions also going to be recorded if you wanted to watch more than one?	Yes, they will be recorded.