

What I learned at GI ASCO

It was wonderful to attend the GI ASCO event last week. I was honored to be there amongst so many brilliant scientists, physicians, specialist and advocates. I learned SO much and felt like I had to write down my experiences so others could benefit as well. Here goes...

- Clinical Trials

I had the misconception that most clinical trials were only available for those that had tried FDA approved treatments and failed. I was so pleased to find that is not the case. There are many clinical trials available to those that have finished treatment to help prevent the disease from returning. There were a couple of trials in particular that I think may benefit this group. I'll list them separately below with links.

- PACES – this trial is actively recruiting 1,500 patient volunteers who have recently been treated for colon cancer. It's a potential drug combo that will prevent polyps from forming. This is for stages 0-III and open. For more complete info, please visit their site. The beauty of this study is you will be more closely monitored for recurrence (one thing I wish I qualified for now, but don't as I'm stage IV)
<http://www.swog.org/patients/paces/>
- There is another trial a doctor mentioned to us that would be something similar but for FAP patients. I am waiting to confirm this info, but I'm fairly certain this is the correct one. If I find another I will share. <https://clinicaltrials.gov/ct2/show/NCT01483144>

Another exciting detail is Chris4Life is partnering with a company to help our patients find clinical trials more easily. Those of us that have attempted to navigate the current government website know how tedious it is, and C4L is working to make it much easier for us. More info to come from them, but I will tell you, it's going to be HUGE! Should make it much easier to find colorectal/anal specific trails based on specific criteria (Foundation One testing or pathology specific and treatment specific). VERY exciting, and I'm so grateful that C4L is investing in this technology for US!

Chris4Life has also been contributing to research and has sponsored a clinical trial as well. It was a proud moment to see their names on the boards (it's a study on anti-CD3 x anti-EGFR-armed activated T-cells for treatment of advanced colorectal or pancreatic cancer) they are fighting for us! I believe this is the correct link

<https://clinicaltrials.gov/ct2/show/NCT01420874?term=minsig+choi&rank=1>

- How to be a "Smarter Patient"

I was fortunate during this trip to have access to some of the most brilliant oncologists in the nation (world) and was able to ask them some fairly frank questions. One of my personal

curiosities was how do WE become better and smarter patients? What can we do to make their jobs easier and more efficient? Here was the short list:

- Seek a second opinion – contrary to how we may feel about “hurting our doctor’s feelings” or “stepping on toes”, they WANT you to seek a second opinion. They also want you to seek that opinion outside of that facility. They said it was very important that you are seen by an oncologist at a major cancer center as well. Most of the time they felt it was fine to treat locally and with a general oncologist, but always seek a second opinion of a GI Oncologist specifically. They will be the most up to date on the latest and greatest data, and will also be more in tune with additional options. You can utilize the NCI website and search my various methods
http://cancercenters.cancer.gov/cancer_centers/index.html
- When you “Google” or find information on additional or alternative cancer treatments, be respectful. They encourage questions, but do not pretend to know more than they do or be questioning their knowledge. They do live and breathe this information, and have much more training and information on the actual data and papers than the Huffington Post. Trust your doctor’s judgment and advice (trust me; I explained that those of us that had been misdiagnosed for years have a hard time with this one!)
- That being said, they want you to be your own best advocate. If something seems incorrect, seek another opinion. They are not perfect, but we as lay people do not have the breadth of knowledge they do.
- If you’re not happy with your current physician, find a new one. This was a BIG one. They said they will never fire you as a patient, and can only suggest you seek care elsewhere; the rest is up to you. They feel it too – if it’s not a “good fit”, you are both better off finding a doctor who is and moving forward.
- Disclose EVERYTHING you are taking, including ALL supplements and alternative treatments (including medical marijuana, Advil, etc...) They are fine with most everything, but need to make sure they do not prescribe anything that could produce an interaction.
- Oxaliplatin dose reduction - Many doctors are adhering to the data supporting a reduction or discontinuation of Oxali once patients begin experiencing neuropathy. Please make sure you are honest with your doctor and tell them at the first sign of neuropathy. Here are some links and info on neuropathy, dose reduction and also the introduction of baby aspirin. There are some docs adding low dose baby aspirin to the mix in order to boost efficacy, and also some docs STOPPING Oxali once neuropathy rears its ugly head. Please ask your doctor about all of this as it may save you from permanent long term side effects. The oncologist I spoke with also said they are rarely making their patients finish a full 12 rounds. Do not feel pressured to do so. Be your own best advocate and work with your doctor to figure out what is right for you. Also ask about low dose aspirin as a possible post treatment therapy to reduce recurrence.
<http://www.cancer.org/acs/groups/cid/documents/webcontent/002908-pdf.pdf>

<http://oncologypro.esmo.org/Meeting-Resources/ESMO-2014/Gastrointestinal-Tumours-Colorectal/Adjuvant-oxaliplatin-dose-and-dose-reductions-are-associated-with-severity-of-peripheral-neuropathy-among-colorectal-cancer-survivors-Results-from-the-population-based-PROFILES-registry>

<http://jama.jamanetwork.com/article.aspx?articleid=184381>

- Urine screening for some gene mutations (KRAS and BRAF) and also HPV

This was new information to me, and I was so pleased to hear that they have a screening for HPV in urine! If you follow the link provided below you can find more info, but for our Anal Buds, this is great news. They are also in the first stages of attempting to monitor patients for recurrence based on the presence of BRAF and KRAS mutations. They are working to improve it now, but it's available. Trovogene is also offering some tests for FREE so they can collect more data of accuracy, so if you qualify it may be worth asking your doctor if it's right for you.

<http://www.trovogene.com/Clinical-Solutions/Oncology.aspx>

- I was informed that there are some wonderful tools to determine your risk for certain cancers. If you utilize their screening tools, you can determine whether or not you are at a higher risk. I encourage all of us to take the hereditary family quiz to see if you or your loved ones are in a higher risk category. This may be the first step in making sure you are screened more closely.

<https://www.myriad.com/patients-families/patient-resources/hereditary-cancer-quiz/>

- Prevention and Advocacy

I'm not sure where to start as there is so much to share! We all know exercise is highly recommended to prevent recurrence (up to 50%!) but there were some others mentioned as well. I know Jeannie DiCarlo shared that vitamin D seems to be something to discuss with your doctor as it may help prevent CRC, and I asked about curcumin, green tea, resveratrol and a few others. There seems to be data to suggest these may be effective to prevent CRC, but may also work synergistically when receiving chemo. Do some research and talk to your doctors. I was pleased to find they are studying more integrative medicine.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3284520/>

What I couldn't have fully comprehended without meeting them in person is just how dedicated our advocate groups are and just how much they do for us and our communities. Chris4Life is putting an enormous amount towards finding cures and funding research, as well as community outreach programs and patient assistance/support programs. Michael Sapienza, Erika Brown and the entire team and Chris4Life/Colontown care about us in a way that touched me deeply and working tirelessly to help find cures and help us navigate the system. I was proud to be in

attendance with their group, and I truly cannot speak highly enough about them as individuals and advocates. <http://www.chris4life.org/> I also found out about other wonderful programs such as the Blue Hope Prevention Award Program through CCA. They help those that can't afford colonoscopies have access to these lifesaving tests, and offer other useful tools to educate the public about screening. <http://www.ccalliance.org/screening/index.html> I hope we all have the opportunity to support C4L and CCA in their efforts to fundraise and also raise awareness by participating in the races and other events that will occur this year.

If you have any further questions or would like any of the data I received, please PM me and I'll get back to you as soon as possible. We are all in this together!