

April 2020

## RE: An overview of PanCAN and PanCAN research efforts

Dear Colleague,

We are so grateful for the research you are conducting to better understand, detect, treat and/or prevent pancreatic cancer. Every piece of data generated in the lab or clinic will bring us closer to our goal to improve and extend the lives of everyone faced with this disease.

During this unprecedented time, we know that pancreatic cancer doesn't stop or slow down – in fact, pancreatic cancer patients are among the most vulnerable in our communities right now. Thank you for staying active with data analysis, virtual meetings, reading, writing and ensuring that research momentum won't stop or slow down, either.

For those who see patients, know that the Pancreatic Cancer Action Network's (PanCAN) [Patient and Healthcare Professional Services](#) are here for you and your pancreatic cancer patients and their families.

The purpose of this letter is to virtually introduce you to our organization and the research we've conducted to improve patient outcomes today and in the future.

**INTRODUCING PANCAN:** Founded in 1999, PanCAN takes a comprehensive approach to fighting pancreatic cancer. We advance research by directly funding grants and raising our voices on Capitol Hill to ensure funding and resources from the federal government.

No organization supports pancreatic cancer patients like we do. We provide more resources and speak with more pancreatic cancer patients and caregivers than any other organization in the world. Healthcare professionals can contact us for personalized services, patient and caregiver support resources, community engagement and government advocacy, and current news, research and funding opportunities. PanCAN ensures patients receive personalized and accurate information to enhance discussions with their healthcare teams and create hope.

Healthcare professionals can [order](#) free, peer-reviewed educational materials to distribute to patients. PanCAN also offers customized clinical trials and molecular profiling resources, and support through our peer-to-peer matching program, the Survivor and Caregiver Network. All information and services are provided free of charge. For more information, visit [pancan.org/for-healthcare-professionals](http://pancan.org/for-healthcare-professionals), email [hcp@pancan.org](mailto:hcp@pancan.org) or call 877-2-PANCAN.

And we are working to raise awareness about the disease and its symptoms throughout the United States and globally in conjunction with the World Pancreatic Cancer Coalition.

Internal research conducted by PanCAN has focused on analyzing the current research and clinical trial landscape, reporting our findings through our Know Your Tumor® precision medicine service, analyzing trends in prescription and compliance with pancreatic enzymes and conducting large-scale analyses to ensure the field is working together to achieve our united goals.

### CLINICAL TRIAL ANALYSIS

- [Nature Reviews Drug Discovery 2019](#)
- [JAMA Oncology 2016](#)
- [ASCO Educational Book 2016](#)
- [J Clinical Oncology 2013](#)

Only about 4% of pancreatic cancer patients in the United States enroll in clinical trials. Although this rate is similar to the average for adult cancer patients, it is too low for a disease for which standard of care treatments provide limited benefit and with a five-year survival rate of just 10%.

We undertook several analyses of the pancreatic cancer clinical trial landscape to better understand why enrollment is low and why trials continue to fail. We found clinical trials weren't necessarily designed to match real-life patient characteristics. We also found that trials were advancing to later stages without ample evidence for efficacy.

Looking to the next generation of clinical trials, PanCAN participated in the Adaptive Platform Clinical Trials Coalition. Adaptive platforms, like PanCAN's Precision Promise<sup>SM</sup>, have the potential to be a faster, less expensive, more efficient way to learn which treatments do and do not work for patients.

Pancreatic cancer patients who participate in clinical research have better outcomes. Clinical trials can advance research and improve treatment options. PanCAN offers clinical trials information personalized for you and your patients through our call center and the most comprehensive, up-to-date database of pancreatic cancer clinical trials in the United States, which is freely accessible through our [Clinical Trial Finder](#).

Some benefits for healthcare professionals to use Clinical Trial Finder include a current, complete overview of the landscape that includes which trials are enrolling patients, a search option for trials based on eligibility criteria and geography and insight into gaps in the clinical trial space to help inform future trial design.

#### **MOLECULAR PROFILING**

- [Lancet Oncology 2020](#)
- [Journal of Clinical Oncology Precision Oncology 2019](#)
- [British Journal of Cancer 2019](#)
- [Clinical Cancer Research 2018](#)
- [Cancer Biology & Therapy 2016](#)
- [Oncotarget 2016](#)

The next step toward increasing patient participation and improving likelihood of positive responses through clinical trials has been our [Know Your Tumor](#) precision medicine service. Our Know Your Tumor service is an IRB-approved protocol that provides healthcare professionals and their pancreatic cancer patients with a molecular profiling report of their tumor, which includes personalized treatment options – including off-label treatments and available clinical trials.

In March 2020, we published results from more than 1,000 patients with pancreatic ductal adenocarcinoma who received Know Your Tumor reports. Consistent with our previous results, 26% of patients were found to have an actionable alteration in their tumor. Through follow-up information, we reported that patients with an actionable alteration who went on a matched therapy had a median overall survival (mOS) of 2.58 years, which is one year longer than those with actionable alterations who went on unmatched therapies (mOS = 1.51 years) or those who did not have an actionable alteration (mOS = 1.32 years).

We have also published analyses of pancreatic cancer patients with alterations in their DNA damage repair (DDR) pathways, showing evidence that treatment with platinum-containing chemotherapy led to significantly increased mOS. There was no prognostic value of DDR mutations in patients who were platinum-naïve. The importance of this finding was underscored by the December 2019 approval of the PARP inhibitor Lynparza® (olaparib) for maintenance therapy for patients with metastatic pancreatic cancer and germline BRCA mutations, whose tumors did not progress after treatment with platinum-containing chemotherapy. This was the first treatment approved for pancreatic cancer patients in a maintenance setting, representing a critical step forward in providing sustained positive responses in patients through a precision medicine approach.

We have shown that molecular profiling of patients with pancreatic cancer is feasible irrespective of their geography or access to an academic center, and that profiling is able to detect rare and potentially clinically meaningful molecular changes in patients' primary or metastatic tumors.

To date, more than 500 physicians – from institutions such as UCSF Helen Diller Family Comprehensive Cancer Center, Johns Hopkins, Virginia Mason Medical Center and Memorial Sloan Kettering – have received Know Your Tumor reports for their patients.

#### **PATIENT AND CAREGIVER DATA**

- [Pancreas 2019](#)
- [The Oncologist 2018](#)
- [Pancreatology 2015](#)
- [J Gastrointestinal Oncology 2015](#)

PanCAN's [Patient Registry](#) is a global online database created to look for patterns in treatments, side effect management and diagnostics that will lead to improved treatment options and outcomes for patients. Through registry data gathered from January 2016 to January 2018, patterns emerged in relation to prescription, usage and symptom management of pancreatic enzymes. Our results showed that patients who took the full dose of enzymes with meals and snacks reported significant improvement of symptoms like indigestion and changes in stool, as well as less weight loss, compared to patients who incorrectly took the medication, underscoring the importance of receiving – and complying with – accurate instructions from their healthcare team.

We and our colleagues also outlined a comprehensive approach for slowing or reversing weight loss in pancreatic cancer patients. The article categorizes weight loss into three causes: anorexia, malabsorption and cachexia, and provides recommendations for assessment and intervention for each cause. The recommendations include regular weight screenings, nutritional counseling with registered dietitians (as appropriate), exercise and pancreatic enzyme replacement therapy. The multidisciplinary team of authors, including members of our Scientific and Medical Affairs team, make up the Supportive Care Committee for Precision Promise, PanCAN's adaptive clinical trial platform.

We have also conducted surveys and published results regarding perceptions of the disease and clinical trials.

#### **LANDSCAPE OVERVIEW**

- [Gastroenterology 2017](#)
- [Cancer Research 2014](#)

PanCAN has also looked at trends and landscape analyses in the field as a whole. Analysis from 2014 predicts pancreatic cancer will become the second leading cause of cancer-related death in the United States by 2030. We've also analyzed the scope of pancreatic cancer research funding from private and public sources.

In order to halt the growing threat of pancreatic cancer, we would like to partner with you to provide patients with treatment options, resources and support that will improve and extend their lives.

[Precision Promise](#) is PanCAN's groundbreaking initiative to dramatically improve outcomes for pancreatic cancer patients. Designed with a nationwide team of leading clinicians, researchers, and diagnostic and drug developers, and backed by FDA, PanCAN's Precision Promise's adaptive clinical trial platform will provide new treatment options for patients and transform the way clinical research is done for pancreatic cancer. There are currently 15 Clinical Trial Consortium sites/locations across the United States, and three sites have opened to date to begin enrolling patients.

**Please visit [pancan.org](http://pancan.org) to learn more.** Contact Kris Bauer, Associate Director of Scientific & Medical Affairs, for more information or any questions at [kbauer@pancan.org](mailto:kbauer@pancan.org) or 310-725-0025.

All the best,

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