Transition Document for the Biden-Harris Administration From Fight Colorectal Cancer

Fight Colorectal Cancer (Fight CRC) is writing to congratulate President Elect Joe Biden and Vice President Elect Kamala Harris on their election. Fight CRC is a national patient empowerment organization dedicated to funding high-impact research endeavors, providing balanced patient education and equipping advocates to influence policy for the collective good. Fight CRC had the honor of participating in the Cancer Moonshot initiative, advising upon clinical trial access and development as well as access to care issues related to patient navigation and barrier reduction. We hope your administration will continue to build on that legacy of support for cancer prevention and control initiatives and we look forward to future collaborations toward our shared vision of reducing death and suffering from cancer.

Colorectal cancer is the second leading cause of cancer death for men and women combined. Prior to COVID-19, it was estimated that 104,610 cases of colon cancer and 43,340 cases of rectal cancer would be diagnosed in the United States in 2020, and a total of 53,200 people would die from these cancers.[1] However, as National Cancer Institute (NCI) Director Dr. Ned Sharpless shared in *Science*, the delay in screening because of COVID-19 could cause an estimated 4,500 additional deaths from colorectal cancer.[2]

Fight CRC respectfully requests that the administration consider the following issues:

- Access to Colorectal Cancer Screening
- Early-Age Onset Colorectal Cancer
- Health Disparities in Colorectal Cancer
- Sustained Federal Funding for Colorectal Cancer Research
- Declare March as Colorectal Cancer Awareness Month

Access to Colorectal Cancer Screening

Unlike with many other cancers, we have the tools to both prevent colorectal cancer and detect it in early stages, when treatment is most successful. When caught early, colorectal cancer has a 90 percent five-year survival rate.[3] One of the most effective preventive services is a screening colonoscopy, which allows for the early detection and removal of polyps that could become cancerous.

Unfortunately, there are still far too many Americans who go unscreened. According to the National Center for Biotechnology Information, roughly 58 percent of all colorectal cancer

[1] https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf
[2] https://science.sciencemag.org/content/368/6497/1290
[3] https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf

deaths in 2020 will be due to "non-screening".[4] While the Affordable Care Act has been a tremendous step forward in ensuring access to preventive screening, for many patients, out-of-pocket costs remain a barrier to accessing timely colorectal cancer screening.

Under Medicare, seniors are eligible for colorectal cancer screening with colonoscopy without out-of-pocket costs. However, if polyps are detected and removed during the course of a colonoscopy, the procedure is then billed as a diagnostic procedure and patients can wake up to a bill of as much as $350. This is a significant barrier to screening in an at-risk population, many of whom are on a fixed income. We urge the Centers for Medicare and Medicaid Services (CMS) to use their statutory authority to waive out-of-pocket costs for patients who undergo a screening colonoscopy and have polyps detected and removed.

This issue is compounded by the fact that COVID-19 has had a significant negative impact on colorectal cancer screening rates. According to recent research conducted by Komodo Health, the number of performed colonoscopies and biopsies fell by nearly 90% from mid-March to mid-April 2020, compared with the same period last year. New colorectal cancer diagnoses declined more than 32% over the same time period.[5] And again, the NCI predicts that this confluence of factors will lead to 4,500 excess deaths from colorectal cancer over the next decade.[6] It is also likely that we will see an increase in more difficult to treat, late-stage colorectal cancer diagnoses as a result of the decrease in screening due to COVID-19.

It is important that individuals not postpone necessary care, including cancer screenings, and should talk with their health care providers about the precautions they are putting in place to keep patients safe. However, colorectal cancer screening is unique in that at-home, non-invasive screening tests are available that can help mitigate the backlog of screenings. At a time when many patients cannot or may not be willing to go into a doctor's office for screening, we believe that encouraging the use of at-home, non-invasive screening tests is a good solution to help keep those at average risk for colorectal cancer up to date on screening during this challenging time. It is important for people to consult their doctor about which test is best for them, but non-invasive, at-home tests such as high sensitivity guaiac-based fecal occult blood test (hs-gFOBT), fecal immunochemical tests (FIT), and multitarget stool DNA test (i.e., Cologuard) are a key way we can continue to screen those at average risk, particularly in areas where access to screening colonoscopy remains limited.

All patients who receive a positive result on a non-invasive colorectal cancer screening test such as those mentioned above should receive a follow-up colonoscopy to complete the colorectal cancer screening process. We urge your administration to take steps to ensure that the follow-up colonoscopy is indeed part of the screening process and is covered with no cost-sharing for the patient. Patients should be able to utilize non-invasive testing options and

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[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4554530/
[5] https://fightcolorectalcancer.org/wp-content/uploads/2020/05/COVID19-Impact-on-CRC-Patients_Research-Brief_Komodo-Health-Fight-CRC.pdf
[6] https://science.sciencemag.org/content/368/6497/1290

complete their screening with a colonoscopy if necessary, without the fear of out-of-pocket costs, particularly during these difficult times.

Finally, we urge your administration to make further investments in the Centers for Disease Control and Prevention (CDC) Colorectal Cancer Control Program (CRCCP). The CRCCP is a data driven program that works to increase colorectal cancer screening among people ages 50-75, particularly in underserved communities. The CRCCP partners with state health departments, universities, and tribal organizations to implement evidence-based programs that have been proven effective for increasing colorectal cancer screening including: implementing a system to remind both medical professionals and patients that it is time for screening, making it easier for patients to get screened by providing transportation and child care, extending clinic hours, simplifying paperwork, and offering patient navigators to help patients through the screening process, and offering multiple screening options approved by the United States Preventive Services Task Force (USPSTF). Particularly, patient navigation to reduce barriers and increase access to care has been the cornerstone of the CRCCP program and an area of priority for Fight CRC. Funding for the CRCCP has remained stagnant for the past several years, limiting the positive impact of the program.

Early-Age Onset Colorectal Cancer

While the majority of colorectal cancer diagnoses occur in individuals over the age of 50, there has been a marked increase in diagnoses among the younger population. Individuals born in the 1990s have double the risk of colon cancer and quadruple the risk of rectal cancer as those born in the 1950s.[7] In 2014, researchers at The University of Texas MD Anderson Cancer Center analyzed data from over 393,000 patients who were diagnosed with colorectal cancer between 1975 and 2010, and predicted that by 2030, one in ten colon cancers will be diagnosed in people under 50 and one in four rectal cancers will be diagnosed in people under 50.[8] In 2017, American Cancer Society (ACS) researchers published in the Journal of the National Cancer Institute that colorectal cancer incidence rates are continuing to rise in young and middle-aged adults.[9]

Early-age onset patients are often diagnosed at a later stage than patients over age 50, when the disease is more challenging to treat. That may be due to delay in seeking medical care, misdiagnosis, or potential genetic and epigenetic differences in the cancer which are not fully understood at this time. We must prioritize research into early-age onset colorectal cancer to develop a better understanding of the risk factors specific to this population and help doctors catch it or prevent it before it occurs. It is impossible to impact clinical care in a meaningful way if we do not know what is causing early-age onset cases and its increasing incidence rates. The NCI has initiated work in this area by issuing a provocative research question around early-age onset cancers broadly. This is an important step, but we urge your administration to prioritize federal research funds for early-age onset colorectal cancer to help future generations who are at a significant increased risk. Fight CRC has convened the leading voices on early-age onset

[7] https://www.ncbi.nlm.nih.gov/pubmed/28376186
[8] https://jamanetwork.com/journals/jamasurgery/fullarticle/1920838
[9] https://academic.oup.com/jnci/article/109/8/djw322/3053481

colorectal cancer to help develop a research plan and we stand ready to support the administration in these efforts.

Health Disparities in Colorectal Cancer

Colorectal cancer incidence and mortality rates are not uniform across race and ethnicity. From 2012 to 2016, colorectal cancer incidence rates among Blacks were approximately 20% higher than those for the white population. This disparity is also seen in mortality rates. From 2013 to 2017, colorectal cancer death rates for Blacks were nearly 40% higher than whites.[10] The disparities don't end there. Black patients are more likely to have advanced stage colorectal cancer at the time of diagnosis, meaning the disease is much more difficult to treat. According to the CDC, rates of colorectal cancer are also higher in all age groups for American Indian/Alaskan Native males and females compared with the white population.[11] Just 59.0% of Latinx/Hispanic Americans age 50-75 are up to date with colorectal cancer screening, compared to 69.2% of non-Hispanic White Americans and 65.5% of non-Hispanic Black Americans.[12]

For many late-stage patients, clinical trials are a critical care option. Unfortunately, despite the higher incidence and mortality rates, Blacks make up approximately 18% of enrollees, while Latinx/Hispanic populations represent a mere 6% of trial participants. In nearly two thirds of clinical trials, there is zero representation from Indigenous communities. The Native American Cancer Research Corporation estimated that 85% of Native Americans wish to take part in clinical trials when they know about them.

Fight CRC is committed to ensuring all Americans have access to quality health care and can live a healthy life, regardless of race, ethnicity, sexual orientation, gender identity, disability, religion, and socioeconomic status. We urge the administration to join us in this commitment and work with us and Congress on policy efforts to ensure health equity for not just colorectal cancer patients, but for all Americans.

Sustained Federal Funding for Colorectal Cancer Research

It is critical that we continue to have robust, sustained investment in colorectal cancer research. As the principal federal agency responsible for cancer research, the NCI has contributed to many of the most life-changing medical breakthroughs for the colorectal cancer community. Additionally, colorectal cancer is eligible for funding through the Department of Defense's Peer-Reviewed Cancer Research Program. The program has provided over $20 million for colorectal cancer research exploring important issues such as whether environmental chemicals are associated with increased risk of colorectal cancer and whether drugs for other conditions can be used to treat colorectal cancer. While we have made great progress in the fight against colorectal cancer, there remains few options for patients diagnosed with late-stage disease. We urge your administration to support increased researched funding for better prevention methods, better treatment options and ultimately a cure for colorectal cancer.

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[10] https://acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21601
[11] https://www.cdc.gov/cancer/uscs/pdf/USCS-DataBrief-No7-May2019-h.pdf
[12] https://progressreport.cancer.gov/detection/colorectal_cancer

Declare March as Colorectal Cancer Awareness Month
Awareness is a key part of increasing colorectal cancer screening rates. To that end, we hope the administration will continue the tradition of recognizing March as National Colorectal Cancer Awareness Month. March was officially designated National Colorectal Cancer Awareness Month by the House, Senate and White House in 1999 after extensive advocacy by the colorectal cancer community. Since that time, awareness efforts have grown tremendously during the month of March as we as a community work towards our goal of reaching 80% colorectal cancer screening rates nationally.

We greatly appreciate your consideration of our priorities and we look forward to working with your administration as relentless champions of hope in the fight against colorectal cancer. We know that you will face many challenges and competing priorities, but we hope you will look to Fight CRC as a resource. For us, this work is personal and we will not stop fighting until there is a cure.