



SURVIVOR VIEWS: Access to affordable, quality health care is as critical as ever

Cancer patients and those who have recently completed treatment are finding it challenging to get necessary health care during the COVID-19 pandemic and many are experiencing financial stress trying to afford care in an increasingly difficult economic environment. We recently asked advocates to share any impact on receiving critical care due to COVID-19 through a Survivor View survey and wanted to highlight ACS CAN Advocate and Survivor Michael Kidonakis' story.

*The Kidonakis family (left to right):
Harry, Michael, Jennifer and Zoe*

Stage IV cancer survivor Michael Kidonakis of Honolulu knows the stress of not getting care during COVID-19. After enduring six rounds of chemotherapy and 35 rounds of radiation in 2017, he thought he had put his nasal (pharyngeal) cancer behind him. However, headaches returned recently and he has been unable to get an in-person appointment for a procedure to check to make sure his tumors haven't returned.

"It's the unknown that is so unsettling," said Kidonakis, a husband and father of 12-year-old twins. "Every symptom feels magnified when you are a cancer survivor and I typically err on the side of caution by getting into the doctor promptly to make sure my cancer hasn't returned. To be unable to do that during the COVID-19 crisis is scary and, with my family depending on me, produces a steady undercurrent of stress."

Kidonakis participated in the latest survey from Survivor Views, a national cohort of cancer patients and survivors who complete surveys on a range of public policy issues important to the cancer community, half (51%) of all those surveyed reported some impact on their care due to the virus. Of those who've experienced an effect, nearly 1 in 4 report a delay in care or treatment. The most common delays were for in-person provider appointments (50%). Among just the respondents who remain in active treatment, more than a quarter (27%) report a delay in their care, and 13% say they don't know when it will be rescheduled.

Nearly 4 in 10 (38%) in the respondents Survivor Views survey say COVID-19 is having a notable effect on their ability to afford their care, due mostly to reduced work hours (14%).

While the economic stress is prevalent across all respondents, the concern is especially pronounced among patients with lower- and middle-class incomes. Nearly half of those earning \$30,000 or less say they're worried about affording their care (46%); more than a third (34%) of those earning up to \$60,000 are worried and a quarter (25%) of those earning up to \$110,000 are concerned.

ACS CAN, is asking Congress and the administration to help patients by providing assistance for people who have lost employer-sponsored health care coverage as well as creating a special enrollment period for Healthcare.gov and increasing state Medicaid programs.

Check out Michael's story: [With focus on COVID-19, cancer patients report delays in getting healthcare](#)
For more information on Survivor View results: <https://bit.ly/2V9TavE>

STATE UPDATE

On May 11th, the legislature will reconvene to focus on the fiscal impact to the state budget. Your ACS CAN team will closely follow the session and reach out if volunteers are needed to advocate for budget issues impacting the cancer community.

We are also working to address patient access issues in an effort to capitalize on the recent Survivor Views survey results including:

- Nonprofit relief in state stimulus packages
- Expanding and preserving access to health insurance through Medicaid
- Potential for tobacco control campaigns

FEDERAL UPDATE

COVID-19 highlights health equity disparities more than ever. ACS CAN is focusing advocacy efforts on patient protections, restarting cancer research and non-profit relief as Congress works on their next stimulus package to address the challenges faced by COVID-19. ACS CAN is advocating for the next Stimulus relief package to include the following measures:

- Increased funding for Medicaid programs.
- Same level of coverage for oral chemotherapy as for traditional IV chemotherapy.
- A special enrollment period so people can sign up for health care insurance.
- Additional financial relief for larger nonprofit organizations, like the American Cancer Society.
- Help restart research and clinical trials at research centers across the nation.



DID YOU KNOW...ACS CAN does not endorse candidates or political parties, and it is not a political action committee (PAC). The organization does educate voters by serving as a trusted source of information about candidate positions on cancer related concerns and on key issue campaigns across the country that impact those affected by cancer. Like cancer itself, ACS CAN is nonpartisan.

Join ACS CAN or Renew your \$10 membership today!

<https://www.fightcancer.org/support-our-work/become-member-acs-can>



Thank you for sharing your stories with us! Cancer will not stop for COVID-19, and neither will we. Are you a current patient or survivor having difficulty getting to your cancer treatments or physician visits? If you or any loved one has been affected by the pandemic let us know how we can advocate for you! Share your story:

<https://www.fightcancer.org/share-your-story>

Or by contacting your Hawaii-Pacific Staff Partner, Cynthia Au, at Cynthia.Au@Cancer.org

Highlighted Past Events: #GivingTuesdayNow

ACS CAN surpassed its goal of 200 donors on Giving Tuesday, May 5th! As part of #GivingTuesdayNow, Buffalo Bills cornerback Levi Wallace teamed up with ACS CAN to raise funds through a Gamers vs. Cancer virtual live stream event and raised over \$5,400! Mahalo to donors and those who shared our message on social media.

You can still give: <http://action.fightcancer.org/goto/Hawaii>



COVID-19 ADVOCACY IMPACT

CANCER HASN'T STOPPED. *So neither have we.*



American Cancer Society Cancer Action Network (ACS CAN) staff and volunteers have worked tirelessly to ensure federal relief packages include provisions to support cancer patients and the health systems and nonprofits that serve them through this pandemic. Here are some of the things we have successfully advocated for so far:

HEALTH SYSTEMS



Funding to support hospital capacity and cover health care providers' COVID-19-related expenses



Funding to support federal, state, local and tribal public health agencies as they prepare for and respond to COVID-19



Extended community health center funding through November 30, 2020 with additional funds to purchase medical supplies and drugs for pandemic response

RESEARCHERS & REGULATORS



Funding for the National Institutes of Health (NIH) to research and develop COVID-19 diagnostic tools, vaccines and therapies



Funding to help the Food and Drug Administration (FDA) review and authorize medical devices, vaccines and therapies to combat COVID-19



Direction to the FDA to identify current and potential drug supply shortages



Funding to support maintaining the Strategic National Stockpile for critical medical supplies, protective equipment and medication

PATIENTS

Access to care provisions that will benefit patients during the COVID-19 crisis, and may specifically benefit cancer patients who are at particularly high risk:



Access to no-cost COVID-19 testing for insured and uninsured individuals



Increased funding for state Medicaid programs to ensure access to low-income and recently unemployed individuals



Increased covered medication prescriptions from 30-day to 90-day supplies for Medicare beneficiaries



Expanded access to telehealth and in-home care for Medicare beneficiaries and veterans



Increased funding for supportive services like nutrition support for seniors

Support for Charitable Giving

Individuals who do not itemize on their tax returns can give now and deduct up to \$300 on their 2020 taxes, enabling them to support those organizations continuing to serve cancer patients and their families nationwide during the current public health crisis.

AND OUR WORK CONTINUES

We continue to survey cancer patients to learn how the pandemic is affecting them and their treatment and using that information to set policy priorities for future aid packages.

Learn more about the relief packages at fightcancer.org/COVIDstimulus.

Join us as we continue to advocate for cancer patients during this crisis at fightcancer.org.

Lights of Hope Bag Decorating Contest

Can't go out and pick up a Mother's Day gift? Mother's Day is right around the corner. Dedicate a Lights of Hope bag to your mom, grandma, sister, and aunt today!

Despite these ever-changing circumstances, our relentless commitment to advocating on behalf of cancer patients and survivors will not falter. Advocates in Hawaii and across the country made their voices heard – calling and emailing with our members of Congress to ensure cancer patients continue to have access to care.

We can't do it alone – we need you, our amazing advocates from across Hawaii, to help us continue to fight for cancer patients and their families, and what better way than through art!

Join the Lights of Hope Bag Decorating Challenge this month and dedicate a bag to your special lady. This activity is fun for all ages!

Enter your bag design to win a prize:

1. Donate to our Lights of Hope page:
<http://action.fightcancer.org/goto/Hawaii>
2. We will send you a Lights of Hope coloring page that can be decorated by being printed out or electronically (Microsoft Paint, Photoshop, etc.).
3. Send the picture of your artwork to Cynthia.Au@cancer.org along with a short description of who you decorated the bag for and why (1-3 sentences).
4. Your entry will be posted to @ACSCANHI Instagram and Facebook LOH May Challenge photo album.
5. Vote for your favorite Lights of Hope bag by liking (1 point), sharing (3 points) and commenting (5 points).

Contest ends at 11:59pm on May 29th. Highest points will receive a surprise gift as soon as we are able to return to the office.

Contact Cynthia at Cynthia.Au@cancer.org or 808-432-9139 with any questions.



Made in Hawaii and displayed at the Lincoln Memorial Reflecting Pool

What is Lights of Hope?

More than 40,000 Lights of Hope bags will be lit across the USA in September and will include touching messages of support, encouragement and remembrance for those who have fought cancer, been a caregiver or lost a loved one. Help us band together to show support to fight this disease.

ACS CAN Hawaii will be honoring our fellow Hawaii friends and family at this very special event and we'd love to have all of those who have bravely battled cancer in our state represented.

Purchase a bag today for \$10. For more information, contact your Hawaii-Pacific Staff Partner, Cynthia Au, at Cynthia.Au@cancer.org or 808-432-9139.

Purchase a Lights of Hope bag:
<http://action.fightcancer.org/goto/Hawaii>

Your bag automatically comes with an ACS CAN membership. You can renew your membership by purchasing a Lights of Hope bag today!

Contributions or membership payments to the American Cancer Society Cancer Action Network, Inc. are not tax deductible.



Bee Positive! It's okay to call family and friends and ask for help when you need it. No one can help you, if they don't know.