Raising Your Voice for Pancreatic Cancer

The Pancreatic Cancer Action Network observes 20 years of grassroots efforts to combat the third-most fatal cancer.

November 21, 2019 By Meave Gallagher

November is Pancreatic Cancer Awareness Month, and the Pancreatic Cancer Action Network (PanCAN) wants everyone to know about this often misunderstood and ignored cancer. This year, after his diagnosis with the disease, Jeopardy! host Alex Trebek has joined with the organization to spread the word—especially about symptoms that no one should ignore.

PanCAN works to raise awareness through patient advocacy, funding research and encouraging earlier detection. Cancer Health interviewed Julie Vasquez, PanCAN's senior manager of public relations.

Tell us about the history of PanCAN—why was it founded, and how has it grown?

In 1996, Pamela Acosta Marquardt lost her mother to pancreatic cancer following a six-month battle. After discovering there was no organization that dealt with pancreatic cancer, Marquardt became determined to do something to ensure that patients and families had a place to turn to for information, resources and hope.

In February 1999, Marquardt founded the Pancreatic Cancer Action Network (PanCAN) with the goal of it becoming a beacon of hope for those touched by the disease.

Julie Fleshman, JD, MBA, became the organization's first full-time staff person and its first executive director in April 2000. Having lost her father to pancreatic cancer in 1999, she has made it her passion and commitment to change the course of the disease. In July 2004, the board of directors appointed Fleshman president and CEO.

November is Pancreatic Cancer Awareness Month. What would you like the public to know about pancreatic cancer?

For too long, pancreatic cancer has been a misunderstood and ignored cancer, but November is our month to make our voices heard and bring greater attention, awareness and better outcomes to this deadly disease. During November, we are asking people to take action to raise awareness about pancreatic cancer, the symptoms and risk factors of this disease, and the urgent need for

earlier detection. PanCAN is the only organization fighting the disease in a comprehensive way, and we are bringing together all of our communities to raise awareness and inspire action during November.

Alex Trebek recently made a public service announcement (PSA) about pancreatic cancer—how did that come about? Are you seeing any direct effects of his openness about his diagnosis and treatment?

Alex Trebek made a PSA for the World Pancreatic Cancer Coalition. PanCAN is a founding member of the WPCC, and Julie Fleshman serves as both the chair of the WPCC and as the president and CEO of PanCAN.

He got involved in the global effort after attending PanCAN's PurpleStride Los Angeles this past May. At the event, he joined 55 other pancreatic cancer survivors onstage and addressed the 2,300 participants, saying, "I have now been a cancer survivor for 60 days, and my hope is that I get to match their accomplishments."

We are so thankful that Alex has used his platform to give a very public face to pancreatic cancer. His decision to become involved in the World Pancreatic Cancer Day global initiative is having a big impact on heightening awareness of the risks and symptoms of this terrible disease.

Alex's PSA has generated significant national and local media coverage. We hope the PSA will continue to garner attention throughout November (Pancreatic Cancer Awareness Month), and especially on November 21 (World Pancreatic Cancer Day), when it will also air during Jeopardy!

As a result of Alex's PSA, we have seen significantly increased traffic to www.worldpancreaticcancerday.org. There, people can learn more about the disease, the symptoms and risks, and how they can take action to raise awareness. They can also find local coalition members who can provide many services and support for people living with and affected by pancreatic cancer.

This year, PanCAN is encouraging the nation to get involved in its urgent fight against the world's toughest cancer through a series of PSAs, which will be highlighted on PanCAN's November Awareness microsite. The PSAs by PanCAN use storytelling to highlight multiple survivor and caregiver stories—helping spread information and awareness on the risks and symptoms of pancreatic cancer—furthering PanCAN's mission to improve patient outcomes.

Is the public aware that pancreatic cancer can have symptoms? What are the main lessons from your PSA campaign that you would like the public to know about?

Because the symptoms of pancreatic cancer are often vague and are generally attributed to other less serious conditions, we want people to know that they may include abdominal or mid-back pain, unexplained weight loss, jaundice, loss of appetite, nausea, changes in stool and new-onset diabetes. PanCAN urges everyone to pay attention to these signs and to speak to your doctor about pancreatic cancer if you experience one or more persistent symptoms.

Volunteers, survivors and participants from San Diego raised awareness for pancreatic cancer during PurpleStride San Diego in September 2019.Courtesy of Pancreatic Cancer Action Network

You have a clinical trial search and matching service—why are clinical trials so important to people with pancreatic cancer and to research into the disease?

Clinical trials often provide the best treatment options, and they give patients early access to cutting-edge treatments that can lead to progress in research, improved treatment options and better outcomes.

PanCAN strongly recommends clinical trials at diagnosis and during every treatment decision. PanCAN's Patient Central can provide information about pancreatic cancer clinical trials, including a personalized list of clinical trials based on the patient's geography, diagnosis and treatment history. PanCAN's Clinical Trial Finder online search tool is also available to patients, caregivers and health care professionals to explore options.

Every pancreatic tumor is different. Patients who receive treatment based on their tumor's biological characteristics have better outcomes. PanCAN strongly recommends molecular profiling of patients' tumors to help determine the best treatment options.

What other kinds of patient services do you offer? What's the best way for people to access them?

PanCAN's Patient Central is the place to contact when facing pancreatic cancer. We provide free, personalized information about the disease, including our support services. We can also find resources for any questions you have related to pancreatic cancer. You can call Patient Central at 877-272-6226 Monday through Friday, 7 a.m. to 5 p.m. PT, or email patientcentral@pancan.org

You have a thriving grants program to encourage scientific research into pancreatic cancer—what are some of the breakthroughs PanCAN has funded or helped fund? How do you choose projects to fund? What's coming down the pipeline in terms of treatment?

PanCAN offers grants for basic, translational and clinical research in pancreatic cancer to scientists and clinicians at various career levels.

Since 2003, we have awarded 174 grants to 170 scientists at 64 institutions. Our total projected research investment is approximately $104 million to date, including our competitive research grants program and leading-edge scientific and clinical initiatives. Each year, grants are awarded through a highly competitive peer-review process.

PanCAN's grantees have deepened the field's understanding of the biology of pancreatic cancer cells in many ways, including identifying new potential therapeutic targets, investigating ways to harness the patient's immune system to recognize and fight off the tumor, discovering biomarkers that could help detect the disease earlier and many other important scientific advancements.

In 2019, PanCAN, in partnership with generous donors, awarded new grants to six scientists to support pancreatic cancer research and awarded five grant extensions to previously funded researchers with projects that are already in progress.

With just a 9% five-year survival rate, pancreatic cancer is the third leading cause of cancer-related death in the United States—what will it take to change that statistic for the better?

Through continued scientific and clinical research, the field is aiming to identify and define populations of individuals who would benefit from screening, as well as develop more effective ways to detect the disease in its earlier stages. Additional research is going toward developing improved treatment options and determining the right therapy for the right patient at the right time.

In June, pancreatic cancer advocates, including 110 survivors, spent the day on Capitol Hill calling on Congress for increased federal research funding as part of National Pancreatic Cancer Advocacy Day 2019.Courtesy of Pancreatic Cancer Action Network

What kind of political advocacy is PanCAN involved in? How can people get involved in advocating for themselves and others?

PanCAN's advocacy efforts are focused on building awareness of the disease and securing support to increase the research investment in the disease. The federal government is the largest source of pancreatic cancer research funding. It is Congress's job to set spending priorities and fund the federal government each year, and therefore, it is important for elected officials to hear from their constituents about the urgent need to invest more in pancreatic cancer research.

Thanks to PanCAN's grassroots advocates, the Recalcitrant Cancer Research Act was signed into law in 2013. The act requires the National Cancer Institute (NCI) to establish scientific frameworks (strategic plans) for pancreatic cancer and other deadly cancers.

People can get involved by urging their members of Congress to prioritize pancreatic cancer research.

What does the PanCAN community do to fight pancreatic cancer? How can people get involved locally?

They can volunteer with a local affiliate to organize community events, build relationships with local media, and meet with elected officials and businesses to spread awareness and raise funds.

And they can participate in a PurpleStride walk in their community.

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