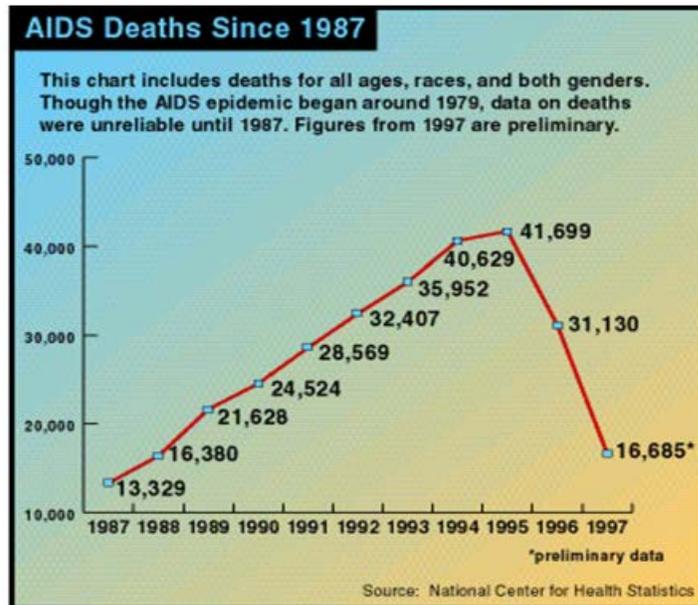


## SU2C/AACR Presentation<sup>1</sup>

August 30, 2018

One of the medical success stories from the end of the 20<sup>th</sup> century is HIV/AIDS, which began decimating American cities in the early 1980s. Its death toll peaked at 41,699 Americans in 1995, before rapidly falling off,<sup>2</sup> but only after billions of dollars<sup>3</sup> of federal research.<sup>4</sup>



Meanwhile, the incidence of pancreatic cancer and its death toll is still rising as federal research funding has been far too low for far too long. Here are some of the facts:

- An estimated 54,400 patients will get this “deadly diagnosis” in 2018; that’s 20 percent more than when I was diagnosed. (*In 2019, the number of diagnoses is estimated at 56,770.*)
- It will kill over 44,000 in 2018 (*and more than 45,000 in 2019*);  
More than 70 percent of these new patients will die within a year!
- It will be the 2<sup>nd</sup> leading cause of cancer death around 2020.

<sup>1</sup> Copyright 2018, Stuart Rickerson, All Rights Reserved. This paper is based on a speech he gave to doctors, researchers and others at the Stand Up To Cancer® (“SU2C”® or Stand Up) Pancreatic Cancer Mini-Summit on August 29-30, 2018. He has served as a Patient Advocate on one of SU2C’s Research Dream Teams for the past 3 years. Rickerson serves on the national Board of Directors of Pancreatic Cancer Action Network (“PanCAN”), and on its Audit and Investment Committee. See [www.pancan.org](http://www.pancan.org). These comments represent only his views, and do not necessarily represent the views of either organization.

Rickerson was diagnosed with pancreatic adenocarcinoma in January 2005, qualified for Whipple surgery, and endured months of chemotherapy, then high beam radiation and follow-on surgeries. He also lobbied for the *Recalcitrant Cancer Research Act of 2013* and has attended every National Pancreatic Cancer Advocacy Day since 2010.

Before diagnosis, he spent 25-plus years as a C-Suite executive and corporate board member in medical device and pharmaceutical field (Eli Lilly & Co., ALARIS Medical, Cardiac Pacemakers/Guidant, Keene Corporation). After his diagnosis, given the grave statistics for the disease, no company would hire him because of the potential risk of his imminent death despite his professional successes.

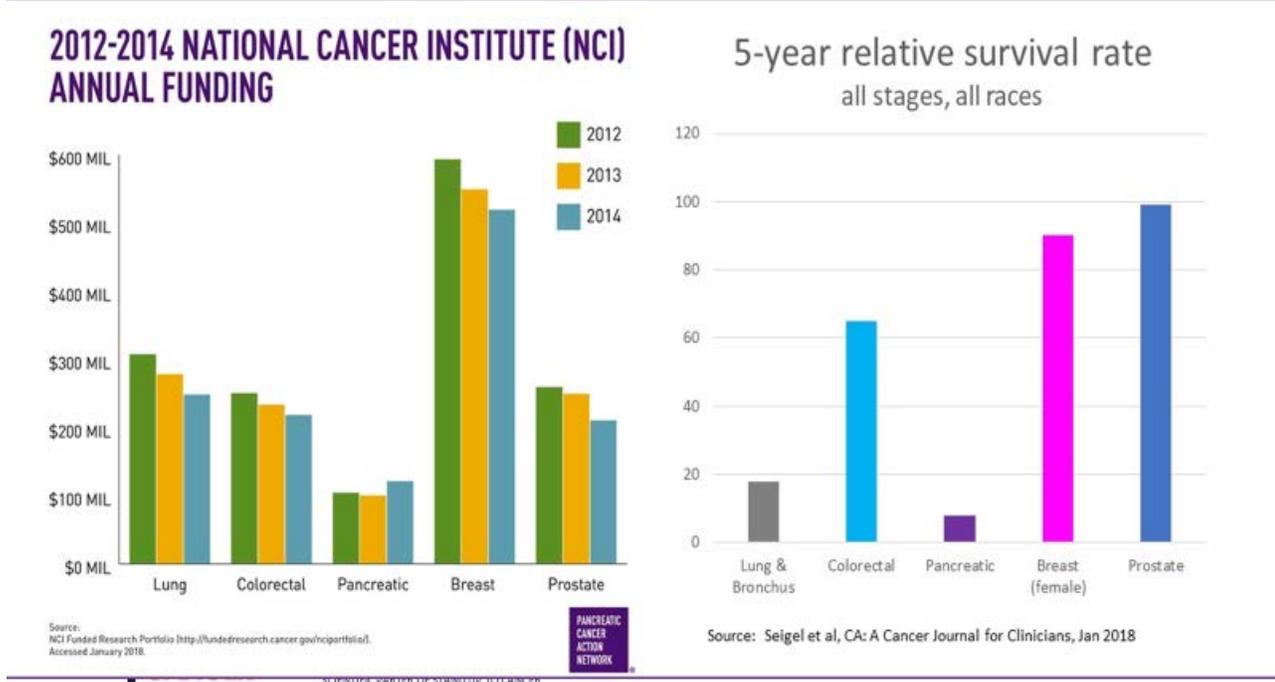
<sup>2</sup> [https://en.wikipedia.org/wiki/HIV/AIDS\\_in\\_the\\_United\\_States](https://en.wikipedia.org/wiki/HIV/AIDS_in_the_United_States)

<sup>3</sup> <https://www.kff.org/global-health-policy/fact-sheet/u-s-federal-funding-for-hivaids-trends-over-time/>

<sup>4</sup> In 2017, 6,700 Americans died from HIV/AIDS.

- Pancreatic cancer is an equal opportunity killer, taking roughly the same number of women as men, and cutting across races and ethnicities more or less equally.<sup>5</sup>
- Few realize that nearly half as many women will die from pancreatic cancer this year as will die from breast cancer.
- Only about 20 percent of us are eligible for Whipple surgery, the 83-year old “standard of care.”<sup>6</sup>
- For most of the rest, the cancer is too advanced.
- Each year, more Americans die from pancreatic cancer than ever died in any one year from HIV/AIDS.<sup>7</sup>

Look at this chart.



Compare the five-year survival rates for five of the deadliest cancers in the U.S. on the right, with the federal funding for those diseases for the same time period (2012-2014) on the left. It’s no coincidence that the deadliest cancer that has the smallest federal research investment also has the lowest survival rate. The U.S. spent just \$17 million on pancreatic cancer research in 1999. Though this has since risen, it is far from being enough to dramatically change the deadly trajectory of this disease any time soon. My main message today is that there must be much more funding, much sooner.

Despite all this “bad news,” there is hope in the pancreatic cancer community. Why the emerging hope? Because this community began raising awareness and demanding more funding. Volunteers from every state began making annual June trips to Congress to demand much more funding. Thousands of others call or write their elected officials each year.

<sup>5</sup> Women: 21,310; Men: 23,020. <https://www.cancer.org/cancer/pancreatic-cancer/about/key-statistics.html> The lifetime risk of pancreatic cancer for men is about 1 in 63. For women, the lifetime risk is about 1 in 65.

<sup>6</sup> <https://en.wikipedia.org/wiki/Pancreaticoduodenectomy#History>

<sup>7</sup> Every 15 months, pancreatic cancer claims as many Americans as were killed in combat in the entire Vietnam War, in which about 58,000 American soldiers and sailors lost their lives in combat.



*With the future coming into sight, this is no time to let up!*

*Now is the time to accelerate the increase of pancreatic cancer research funding levels.*

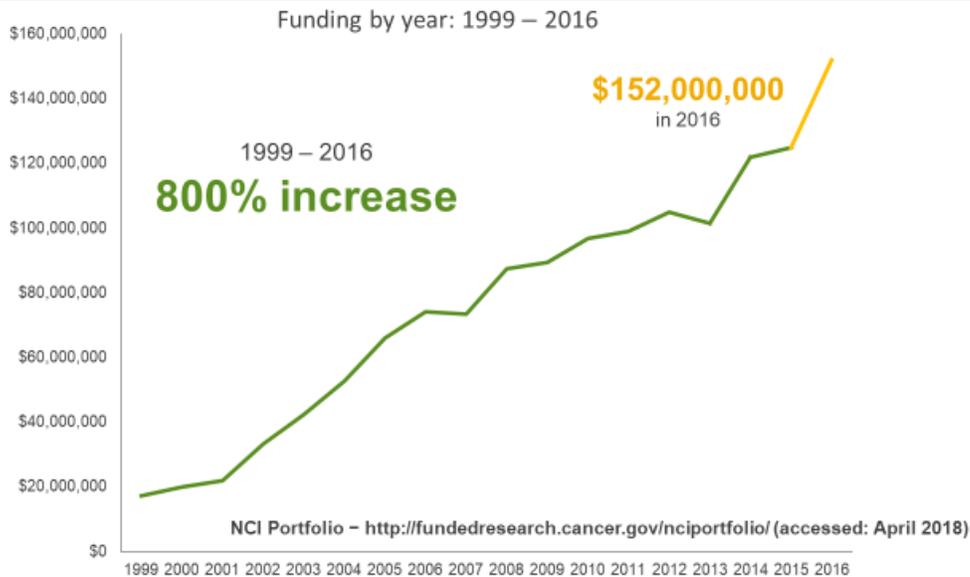
Rickerson (L) and Michael Weinstein another survivor march to Capitol Hill at PurpleStride<sup>®</sup> – Washington to demand greatly increased federal research funding for pancreatic cancer.



On my first trip to D.C., a Congressman asked: “Why don’t we see hundreds of survivors like we do with other cancers?” I replied, “Because we mostly die quickly.”

They don’t ask that question anymore. We’ve taught them some things about the disease and the way it strikes adults of all ages.

## National Cancer Institute (NCI) Pancreatic Cancer Research Funding (1999-2016)

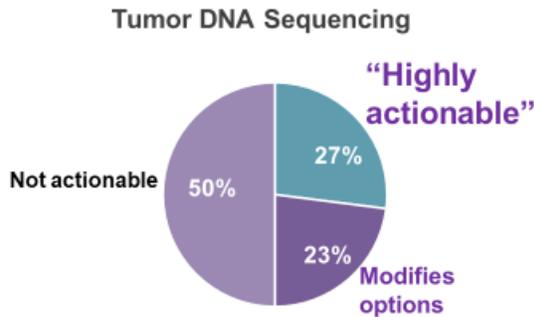


As a result, funding levels finally are beginning to rise, slowly at first and with increasing momentum. The research funded in recent years is beginning to show results. As a result of this new funding, new treatments are available or coming on-stream. New approaches are being tried. New research is also exploring genetic links to this disease. Leading institutions are doing molecular profiling to provide “precision or personalized medicine” with statistically significant effect.

Federal funding levels still are not nearly high enough, especially compared with the still rising incidence rate and still rising death rate.

**MOLECULAR PROFILING OF PANCREATIC CANCER PATIENTS:  
INITIAL RESULTS FROM THE *KNOW YOUR TUMOR*® INITIATIVE**

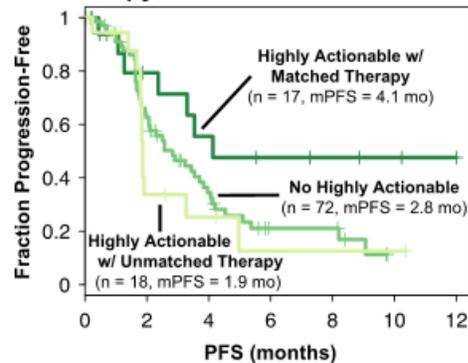
June 2014- August 2017, 640 reports (now up to 932 reports)



Pishvaian et al, *Clinical Cancer Research*, online June 28, 2018



**Patients with highly actionable alterations who received matched therapy had improved progression-free survival (4.1 vs 1.9 months) over those that did not receive matched therapy,  $P=0.03$**



This slide is from the first Know Your Tumor® paper published in June 2018, showing that precision medicine, or medicine designed with a particular patient and their tumor in mind, works in pancreatic cancer patients. It shows that having an actionable alteration *and* getting on a targeted treatment results in longer life than having an actionable alteration and not getting on that targeted treatment.

Know Your Tumor® is inspiring new hope for pancreatic cancer patients – and researchers!

Meanwhile, to make up for some of the federal funding shortfall, advocacy groups and individuals began stepping up, most notably Stand Up To Cancer, some pharmaceutical companies, foundations and some large donors. Other funding sources opened up too.

A huge “shout out” to all who are helping. You are creating HOPE!

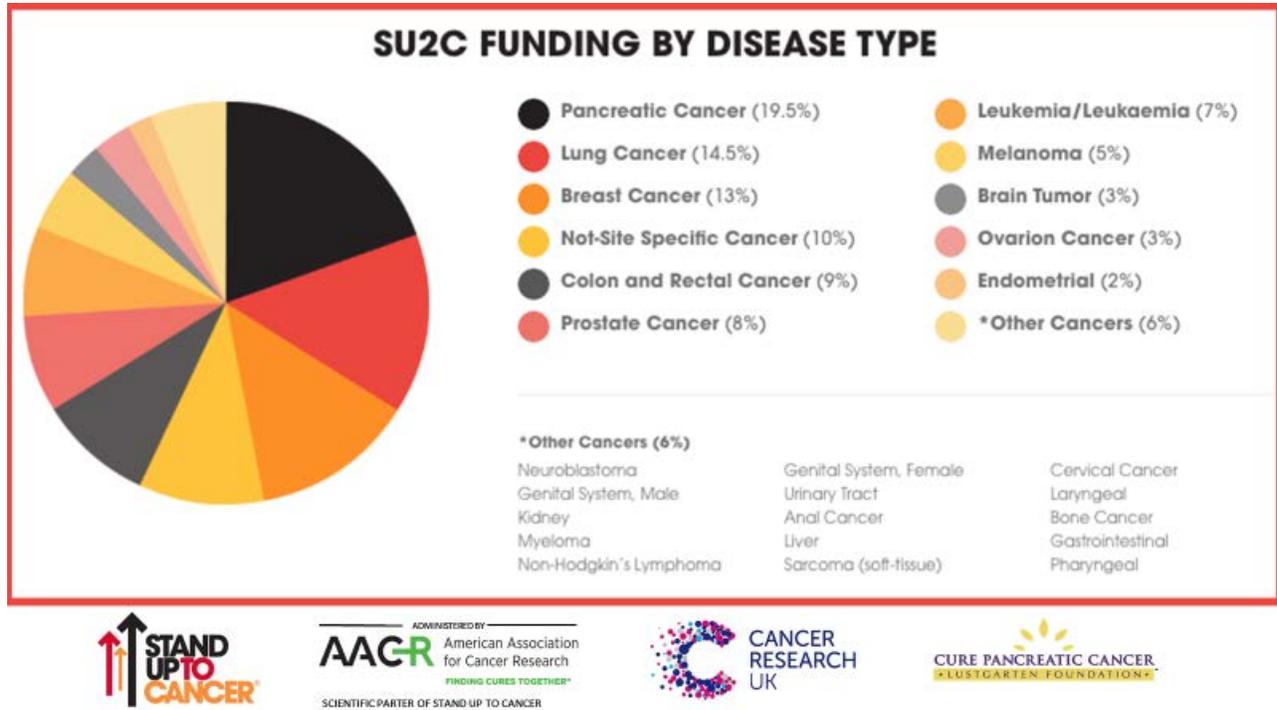
The Pancreatic Cancer Action Network, the nation’s leading pancreatic cancer advocacy and patient support organization, has made grants to 167 scientists at 62 institutions (at the time of this presentation). Research is its No. 1 budget “spend,”<sup>8</sup> while still delivering leading-edge patient support and advocacy. PanCAN has invested over \$56 million in research and attracting scientists to this cutting-edge field. PanCAN’s grant recipients leveraged these grants 11-times-over in follow-on pancreatic research funding. That is over half a billion dollars on pancreatic cancer research! Over the years, the Lustgarten Foundation funded \$154 million in total grants.<sup>9</sup> Rather than advocacy or patient support, it pledges “100 percent of donations go to pancreatic cancer research.”<sup>10</sup>

<sup>8</sup> <https://www.pancan.org/research/grants-program/grants-awarded/>

<sup>9</sup> [https://issuu.com/lustgartenfoundation/docs/final\\_lustgarten\\_17ar\\_may\\_24?e=29972399/62749555](https://issuu.com/lustgartenfoundation/docs/final_lustgarten_17ar_may_24?e=29972399/62749555)

<sup>10</sup> <https://www.lustgarten.org/howyourmoneyisspent>

And, then there's SU2C. Unlike U.S. funding tables, Stand Up's No. 1 research "spend" is on pancreatic cancer with nearly one in five of its research dollars going to pancreatic cancer researchers.<sup>11</sup> Look at this chart:



The U.S. government should follow Stand Up's lead by dramatically increasing its funding on this deadliest of deadly cancers! That was how it changed the future for those at risk of HIV/AIDS in the 1990s.

It's a basic maxim in business, and one that applies equally to medical research: "Where you invest, you get results." And the counterpart is: "Where you don't, you don't." That has certainly been true with pancreatic cancer.

These increases in research funding are beginning to show results: After 50 years with a five-year survival rate stuck at 5 percent, the rate rose to 9 percent by 2018. As an example of what can be done when funding levels rise, the far more robustly funded federal research into prostate and breast cancer shown in the earlier chart have increased their five-year survival rates to 99<sup>12</sup> and 90 percent,<sup>13</sup> respectively.

Pancreatic cancer is still the only major cancer with single-digit five-year survival. But this is still an 80 percent improvement. And, with continuing and increasing research funding, the pancreatic cancer survival rate can rise dramatically!

Eighteen months ago, when I spoke at the SU2C scientific conference, I said I thought, "The future was just over the horizon." I feel even more "bullish" now. Today I say, "The future is in sight; we just have to adjust our telescopes to see it."

Here's one tangible example. Nearly five years ago, the Pancreatic Cancer Action Network set challenging twin goals: to raise \$200 million and, seemingly even more challenging, to double the survival rate for this disease by 2020. Now, two years out, both seem possible!

<sup>11</sup> <https://standuptocancer.org/what-we-do/where-the-money-goes/>

<sup>12</sup> <https://www.cancer.org/cancer/prostate-cancer/detection-diagnosis-staging/survival-rates.html> Ten-year survival is 98%.

<sup>13</sup> <https://www.healthline.com/health/breast-cancer/survival-facts-statistics> Survival varies depending on the stage of the cancer, while this is the survival rate for all those diagnosed.

With the tipping point on this cancer nearing, this is no time to let up! Now is the time to accelerate funding levels and to increase private donations to leading pancreatic cancer advocacy groups which also fund meaningful research.

I know Stand Up 2 Cancer and its scientific partner, the American Association of Cancer Research, fund research for many different cancers and bring all of us together under this Big Tent to end cancer. Whatever the cancer, the work these researchers, clinicians and scientists are doing is inspiring!

I do not look at research dollars as a “zero sum” game, however, where research funding can go to one group only if another group gets less. So, it’s not an “either/or” choice. The U.S. federal government spends billions each year on medical research. For example, U.S. funding for HIV/AIDS research still *averages* \$2.7 billion *per year* more than 20 years after the death rate peaked. It spends much more on other support and treatment costs.

America is also the most generous country in the world. More than \$400 billion is given to charity each year, nearly \$300 billion by individual donors.<sup>14</sup> Many wealthy Americans have signed the “Giving Pledge” to give away most of their wealth in their lifetimes. Right now, more than \$100 billion is growing in Donor Advised Funds,<sup>15</sup> just waiting to be directed to worthy causes. We should be reaching out to Fidelity, Vanguard, Schwab and the Silicon Valley donor-advised funds heads and making the case for our cause. I’m convinced that with the right message, inspiration and motivation, funds will flow! These donors have the chance to literally “change the future” for hundreds of thousands of Americans, their families, friends and work colleagues. How often do you get a chance to do that?

We should ask generous Americans to change the course of this disease forever, beginning with the annual September Stand Up 2 Cancer telethon and in individual “asks” throughout the year. With a 1 in 64 lifetime-risk,<sup>16</sup> until we know its cause, no one is immune!

If you do not feel comfortable making the “ask” yourself, talk to the stewardship chair of your local PanCAN affiliate or call PanCAN and let them see if they can “connect the dots.” Meaningful new funding will help researchers find a cure and change this “deadly diagnosis” into a “chronic condition” for most.

Vice President Biden calls for a “cancer moonshot.” For those of you who are not old enough to remember, let’s examine what he means:

1. President Kennedy asked Congress in early 1961 to “commit [this Nation] before this decade is out [to] landing a man on the moon and returning him safely to earth.”
2. In that speech, JFK predicted it would take “many years and carry very heavy costs.” To get to the moon and back in 1969 cost over 100 billion in today’s dollars.<sup>17</sup>
3. Then in what is usually forgotten, he cautioned, “If we are to go only halfway, or reduce our sights in the face of difficulty ..., it would be better not to go at all.”

What if \$1 billion were invested in pancreatic cancer research for each of the next 10 years, not just \$152 million? That’s how the federal government, motivated by constituent pressure, turned the tide on HIV/AIDS and other deadly diagnoses in the past, including breast cancer, polio, swine flu and so many others. When the U.S. government finally prioritizes finding medical solutions to seemingly intractable diseases, improved outcomes and even cures result. What

---

<sup>14</sup> Over \$400 Billion is donated to charity each year. NY Times. 8/18/18, news summary, p. 3.

<sup>15</sup> NY Times, 8/12/18 business section. The article reports \$85 Billion in 2017; with 52-week stock market increase of approximately 18% since then, this sum should have grown to at least \$103 Billion by mid-year 2018 – even if zero further donations were made. In fact, 2017-2018 saw billions more donated to these funds, so this is a conservative estimate.

<sup>16</sup> <https://www.cancer.org/cancer/pancreatic-cancer/about/key-statistics.html>. The average lifetime risk of pancreatic cancer for men is about 1 in 63. For women, the lifetime risk is about 1 in 65.

<sup>17</sup> <http://www.thespacereview.com/article/1579/1>

are we waiting for? How long must pancreatic cancer patients and their families suffer before their cause becomes a priority?

Here are just a few, obvious things that would begin to happen, and relatively quickly, with more federal funding:

- You'd attract many more brilliant scientists to this field.
- You'd get actionable results much faster.
- You'd save thousands of lives.
- You'd extend survival by many years.  
Personally, I believe that with proper funding levels and smart research, survival rates can double from current levels by 2025, and then double again by 2030.
- You'd also save billions of dollars in social, economic and insurance costs.

Collectively, we'd surely save billions of dollars in treatment costs – and at least \$4 billion in lost patient income each year. I'd even make the case that \$1 billion in new funding for pancreatic cancer would soon pay for itself in increased income tax revenue on this lost income!<sup>18</sup>

If we increase pressure for federal funding to reflect the death toll from this disease, we will be investing where the return likely is the greatest. Here are a few specific, easily achieved actions that could make a real difference in the meantime.

What if Stand Up and other advocacy groups mobilized its constituents to contact their representatives to demand much higher pancreatic cancer funding on the next PanCAN Advocacy Day, June 25, 2019? With thousands or tens of thousands additional constituent calls, this small step would likely move the funding needle up much faster.

Increased federal funding brings up a different issue: Without more patients in clinical trial you won't fill those newly funded trials. Only 4.2 percent of pancreatic cancer patients enter trials now. That's just over 2,000 patients per year. In that SU2C speech 18 months ago, I gave some specific ideas on how to increase this participation rate. Many of those ideas are explained on <https://www.pancan.org/facing-pancreatic-cancer/treatment/treatment-types/clinical-trials/faq/> or in my poster presentations.

The fact is that pancreatic cancer patients who participate in clinical trials have better outcomes. Yet, 75 percent of pancreatic cancer doctors do not recommend clinical trials to their patients! Stand Up is running ads so more cancer patients will enroll in smart clinical trials. That's a great start. We also need to educate treating doctors and get rid of nihilistic – and wrong – medical beliefs about clinical trials and this disease.

---

<sup>18</sup> Average U.S. pay, about \$80,000 times 55,000 annual diagnoses equals \$4.4 billion/year lost income. Assuming either a 10 or 25 percent marginal tax rate, the lost income tax revenue would equal \$400M to 1.1Billion.

“Clinical trials bring us closer to the day when all cancer patients become survivors.”

Go to: [Su2c.org/ClinicalTrials](https://Su2c.org/ClinicalTrials) to learn more



## STAND UP FOR US ALL

Clinical trials bring us closer to the day when all cancer patients can become survivors.

Clinical trials are an essential path to progress and the brightest torch researchers have to light their way to better treatments. That's because clinical trials allow researchers to test cutting-edge and potentially life-saving treatments while giving participants access to the best options available.

If you're interested in exploring new treatment options that may also light the path to better treatments for other patients, a clinical trial may be the right option for you. Speak with your doctor and visit: [StandUpToCancer.org/ClinicalTrials](https://StandUpToCancer.org/ClinicalTrials) to learn more.



Part of the problem is that patients want treatment, but many patients I speak with still think trials involve either taking a real medicine or a placebo. That's just not true. Cancer trials typically involve either getting the “state of the art” treatment or getting that standard, *plus* promising new treatment options. Doctors must do a much better job explaining the options available to pancreatic cancer patients! This is explained clearly on both <https://clinicaltrials.pancan.org> and <https://standuptocancer.org/for-patients/clinical-trials>.

The fact is, when patients do call existing help lines, and are told what cancer clinical trials really mean, trial enrollment goes up 3 or 4 times. If that happened, there'd be 6,000 or 8,000 more pancreatic cancer patients participating in clinical trials. Their outcomes are likely to be better, and we would get to more answers more quickly.

What if there were much more publicity and more support for existing pancreatic cancer call centers, like PanCAN's Patient Central?<sup>19</sup> More patients will call, resulting in far more patients participating in clinical trials and advancing the knowledge on how to treat pancreatic cancer patients!

Treating physicians, Stand Up To Cancer, AACR, and even other advocacy groups should refer pancreatic cancer patients to these call centers to help patients make decisions about their care, including clinical trials. Stand Up requires researchers on its Dream Teams to work together on all of the research it funds. Asking treating docs and advocacy groups to collaborate to help patients in this way does not seem like a “stretch.”

One last thought: What holds the greatest hope for pancreatic cancer patients? Detecting this disease earlier. Early detection is the “silver bullet.” With earlier detection, these rogue cells could be treated or excised before they spread. It's hard to believe, but there still is no PSA or blood test, no colonoscopy or mammography equivalent, that effectively screens for pancreatic cancer.

The fact is that when diagnosed early, survival rates can reach 40 percent, even today! Think what a reliable screen for pancreatic cancer – ideally one that is relatively inexpensive or minimally invasive -- would do. One only has to look at the advances resulting from PSA tests for prostate cancer, mammography for breast cancer, skin biopsies for skin cancer, colonoscopy for colon cancer or chest X-rays for lung cancers.

<sup>19</sup> Call Pancreatic Cancer Action Network's Patient and Caregiver Support: [877-272-6226](tel:877-272-6226). Monday through Friday, 7 a.m. - 5 p.m. PT

## Earlier Pancreatic Cancer Diagnosis = Much Better Outcomes

### DIAGNOSED EARLY



5-year survival rate **40+ %**<sup>1</sup>

### DIAGNOSED LATE



5-year survival rate **< 5 %**

1. Ann Surg Oncol (2017) 24:2023–2030



Doctors would find this cancer years earlier. I used to think the survival rate was so low because pancreatic cancer cells spread so quickly. But research has shown that my assumption was wrong. In fact, these tumors often start growing 10 to 20 years before being detected. Early diagnosis will allow doctors to attack this cancer before it has spread, or when the tumor is still small and localized.

Again, we need, much more research funding. That too is changing.

- Stand Up and the Lustgarten Foundation have formed several new Dream Teams focused on earlier detection.
- More dramatically still, PanCAN and the National Cancer Institute are working on a unique private-public partnership on an Early Detection Initiative and raising funding, including seeking at least one \$5 million lead donor, to launch what ultimately is likely to be a \$25-50 million joint project. As a survivor, I hope this gets funded soon so the work can begin and we can start to get to the answers!

If you want to change the future, and you're a philanthropist or company that wants to be in this space, PanCAN's Early Detection Initiative would be something you should rush to fund.

Wouldn't it be great to see a future chart showing sharp declines in pancreatic cancer deaths, like the one shown earlier?

**Wouldn't it be great to be able to say, "I had something to do with changing the future for pancreatic cancer patients."?**

To transform the future of this disease forever, early detection is worth funding – the sooner and the larger the better.

I especially want to thank Stand Up To Cancer for asking me to speak to these brilliant scientists again today as an advocate for patients with pancreatic cancer. SU2C has the biggest megaphone and the largest spotlight to shine on this too long neglected equal opportunity killer cancer. And in case you missed the poster session, here's the one I presented yesterday on behalf of our Stand Up Pancreatic Cancer Dream Team:

**Shoot for  
the MOON!**

**“Until we find a cure, let’s at least convert pancreatic cancer  
from a ‘deadly diagnosis’ into a ‘chronic condition.’”**

**Demand substantially  
higher funding for  
pancreatic cancer research:**

- The case is compelling
- Invest where potential return is the greatest
- #2 leading cause of cancer death by 2020
- Incidence is still rising
- Science and medical research should replace *luck* as a reason some pancreatic cancer patients surviving 5 years, while 91% do not.

- ❖ **Give patients and their families more reasons for HOPE**
  - You can't have hope when you're told to give up!
  - Train your team to **stop telling patients** to “go home, put your affairs in order and hug your families and friends goodbye.”
- ❖ **Science and medicine is improving:**
  - New treatments are available. More are on their way
  - Earlier diagnosis mechanisms are just over the horizon
  - Survival rates should double by 2020 -- and could double again before 2025
- ❖ **Encourage patients to:**
  - Get a second opinion
  - See a specialist or go to pancreatic cancer center of excellence
  - **Seriously consider clinical trials**
  - Consider molecular profiling and precision medicine
- ❖ **Be audacious; Be aggressive:**
  - **Pancreatic cancer patients are willing to take greater risks**
  - Design more patient-centric clinical trials
  - Don't waste precious resources: money, time -- and **most especially patients**
  - **Expand eligibility for clinical trials and eliminate artificial disqualifying criteria**
  - Open trials around the country to speed accession and reduce accrual time
  - Require “early-stop” rules to end accrual in minimal efficacy studies

**EXCERPTS FROM 2018 SU2C Scientific Summit Poster Session**

I am inspired by the tight collaboration of these brilliant researchers from so-called “competing” Centers of Excellence. I also am inspired by our Immunology Dream Team, which conducted “science in patients” studies in more than 600 pancreatic cancer patients to see how the microenvironment changes when attacked by novel treatments. Like getting to the moon and returning safely, it will take longer than the three years we had to learn from these studies. Funding ran out this year. To their credit, team members pursued other funding sources to get to the answers. Their papers will be published in medical journals in the future.

I leave you with this challenge: Whatever your specialty and whatever your area of focus, I urge you to remember the takeaways from JFK’s vision. If your goal truly is a Cancer Moonshot,

- (1) You’ve got to aim high,
- (2) You have to work together
- (3) You have to have enough time, and most especially,
- (4) You must have enough funding!

Otherwise, as JFK said, “it’s better not to try at all.”

Working together with adequate funding, I predict we will change the world for future pancreatic cancer patients. It’s just a matter of when.

Let’s make pancreatic cancer one of the medical success story for the early 21<sup>st</sup> century!