

A stylized teal figure with a circular head and a body that tapers at the top and bottom, resembling a person with arms and legs outstretched. The figure is set against a light blue background with a faint, large-scale DNA double helix structure. The text 'ican' and 'in Brief' is overlaid on the figure's body in white.

ican
in Brief

ICAN in Brief

ICAN's goal is to extend life with the highest possible quality of life. A unique patient advocacy charity, ICAN serves patients across the U.S. and in 53 countries, managing the details of the patient's cancer case, interpreting molecular profiling reports, and researching personalized medicine options, clinical trials, and when appropriate, getting approval for the compassionate use of anticancer drugs.

What ICAN Does for Patients and Their Families

Taking the Patient Back from the Precipice to Complete and Durable Remission

An ovarian cancer case at ICAN is entering her 12th year of remission. This case had everything going against it: many, many months of misdiagnosis, serious symptoms, and a dismal outlook. Given the expertise of ICAN's Physicians Council on ovarian cancer, this patient was armed with the best treatment protocols from the start. Many years later, other than lab work and imaging to make sure that the ovarian cancer has not recurred, she has not needed additional treatment and has been fully enjoying life. Cancer status: Disease-free! Life extension: 12 years. Healthy!

Never Letting a Patient Get Written Off

After a colon cancer patient was "written off" and told by a renowned cancer center that she was a hopeless case, the patient consulted ICAN, which recommended that she consult new oncology teams and that she talk to her new oncologist about a specific clinical trials drug. The patient went on the drug and has been in remission for more than 11 years with high quality of life.

One of ICAN's breast cancer patients was diagnosed more than 8 years ago with metastatic cancer and told that her options were few and that the situation was bleak. A friend of hers who was a volunteer for ICAN's Jewels of the Sea Ball, referred her to ICAN. Following ICAN's referral to a top breast oncologist who was working closely with a leading-edge tumor vaccine clinical trial group, the patient remains disease free today. In every speech this patient gives (her ICAN case was profiled in *Newsweek* magazine in 2011), she says that "ICAN saved my life." Life extension: 8 years. Healthy, happy, and living her life!

A metastatic prostate cancer case came to ICAN after having been "written off" by one of the country's most famous cancer centers and told that there was nothing else that could be done. ICAN found the patient a new team and was with the patient at every major and minor decision crossroads during his battle. The patient credited ICAN with "saving (my) life not once but three times." Life extension: the patient enjoyed three additional years with high quality of life.

Getting the Diagnosis Right to Be Able to Treat Effectively

One of ICAN's patients on the east coast was diagnosed with lung cancer. The ICAN advocate who the patient was working with thought that the pathology report was inaccurate and incomplete. ICAN recommended that a second opinion be obtained on the pathology, and the second opinion concluded that the patient had renal cell carcinoma instead of non small cell lung cancer. Having the correct diagnosis, the patient can now be treated for the cancer that he has, not the incorrectly diagnosed cancer.



A "cancer of unknown primary" patient comes to ICAN seeking help. She has been treated with standard chemo regimens, but her team has had no idea as to where the cancer originated. Since ICAN is very involved with tumor sequencing and molecular profiling and works with the leading laboratories across the country, ICAN contacted a state-of-the-art lab involved in determining cancer of unknown primary cases. After the lab analyzed the patient's tissue, the patient was told that her primary cancer was highly likely to be kidney cancer. She is now able to take the correct drugs for kidney cancer and has a much more hopeful prognosis in light of the gains made in kidney cancer therapeutics over the last several years.

Obtaining the Best Surgical Plan, Even if the Patient's First Team Ruled Surgery Out

The family of a young man with colon cancer sought ICAN's assistance. He had a large tumor in the colon and a large tumor in the liver. The first surgical oncologist he consulted would only operate on the colon tumor. ICAN suggested the need for second opinions, both of which confirmed ICAN's view of the case that both the colon surgery and the liver surgery could be handled simultaneously. Nearly three years after the "double" surgery suggested by ICAN, the patient remains disease-free. Had his liver tumor not been removed, he would have lived only months and not the years he has now been enjoying.

A newly diagnosed pancreatic cancer patient came to ICAN and asked for our help, telling us that a surgeon had told him he was completely inoperable. ICAN reviewed the imaging reports and concluded that there was a chance that a Whipple procedure (a very complex and extensive pancreatic surgery which is appropriate for only 15% of pancreatic cancer cases) could in fact be possible and recommended that the patient seek a second surgical opinion. The second surgeon in fact concluded that the patient was operable, and Whipple surgery was performed, adding years to this patient's life.

A melanoma patient with whom ICAN had been working since diagnosis told us that surgery to the metastasis in her chest area had been ruled out. ICAN provided the patient with the literature showing that surgery was in fact possible in her particular case. Successful surgery was performed by a leading team, and the patient remains disease free for more than four years, thanks to not only the success of the surgery but a promising immunotherapy clinical trial.

Making Sure the Medical Team Talks to Each Other and Communicates With the Patient

ICAN was the advocate for a gentleman whose complex case had involved what we call "diagnostic whiplash"—receiving ultimately three completely different pathology reports, each of which were diametrically opposed and involving different treatment options. When the patient got to ICAN, he was demoralized and without hope, having been told there was nothing that could be done. He had a team of physicians who were not communicating with each other or with him. ICAN referred the patient to two new oncology teams that would pursue clarity on the pathology issue, empowered the patient and the family to be able to ask the right questions, and made sure that the patient insisted that all the specialists involved—on what initially began as a very fractured team—communicated with each other, the

patient, and the patient's family. This case involved daily case navigation between ICAN and the patient's family. Even though the patient ultimately died of unexpected complications, the patient and family were confident that everything possible had been done and that no stone had been left unturned in the final chapter of the patient's life.

Obtaining Every Possible Benefit for the Patient from the Latest Advances in Molecular Profiling

ICAN educates patients and their medical teams about molecular profiling and new therapies so that they can truly enter this era of personalized medicine. One of ICAN's pancreatic cancer patients asked his medical oncologist, at ICAN's request, to order molecular profiling to better understand his tumor. When the reports came back, ICAN explained in detail what they meant, and the patient's oncologist admitted that he would have put the patient on the wrong chemotherapy if he had not had received the critical information from the reports that ICAN had urged that the patient and his medical team pursue. While the patient ultimately lost his battle with pancreatic cancer, the family has told ICAN that he lived at least one year longer with high quality of life because of ICAN's advocacy services.

Researching the Most Appropriate Clinical Trials

A gynecologic cancer patient had been told nothing further could be done in her treatment plan. A close friend of hers urged her to call ICAN. ICAN analyzed the medical record, and based on the patient's diagnosis, history, and molecular profiling, ICAN referred her to a leading Phase I novel therapeutics expert who handles promising clinical trials at a leading cancer center to ascertain if certain inhibitors would be appropriate for her particular cancer. The patient now has several clinical trials options as well as other options from the standard pipeline relevant to her particular cancer. In two weeks, the patient went from no options to quite a few options.



Dealing with the Life-Extending Details on Cutting Edge Personalized Medicine-oriented Laboratory Analysis

A very rare cancer case which oncologists might see in decades of practice was treated with top teams on both coasts. Even when leading teams are involved, there can still be delays, communication problems, conflicting opinions, and general frustration, especially for the patient and his proactive family. ICAN is taking the lead sorting through all the molecular profiling and sequencing options with the patient in order to best position the patient going forward with new therapeutic avenues derived from the insights contained in the molecular profiling reports. Without ICAN's analysis and the involvement of ICAN's Biomarkers Council, the patient would have far fewer options going forward.

Implementing the ICAN Goldilocks formula: Treatment Can't be Under-treatment, and it Can't be Over-treatment Either

ICAN was referred to a breast cancer patient who was sent home to die, having been told that she would live no longer than a year. ICAN understood immediately that the patient was being undertreated and referred her to a top breast oncologist in another state. She is alive and doing very well three years later.

Performing Special Miracles to Get the Right Drug to the Cancer Patient No Matter What the Obstacles

One of ICAN's Australian patients was unable to get a drug that would be crucial to extend her life. The drug had been approved in the U.S. and in other countries but not in Australia. ICAN called the vice president of oncology for the pharmaceutical company involved, and the Australian oncologist who was treating the patient was shocked upon receiving a hand-delivered courier package of the life-extending drug, and was delighted that ICAN's compassionate use request had succeeded.

ICAN was asked to become involved on a case that was receiving a great deal of national attention on the issue of compassionate use for a pediatric patient battling what could be a lethal infection in his immuno-suppressed state. Without the talents of ICAN's top legislative affairs specialist in Washington, D.C., the ultimate resolution of this pediatric cancer compassionate use case would not have happened. Several weeks after receiving the life-extending drug, the child was released from the hospital to go home. ICAN is now working with members of Congress on a national fix for the compassionate use area.

A patient with a very rare cancer sought our assistance in dealing with her local oncology team and the center where she was receiving a second opinion. Realizing that both teams had failed to handle her case in a proactive fashion and had essentially given up on her, ICAN referred her to a third oncology team which, after molecular profiling was requested, understood that a certain drug used primarily in another cancer would be very promising for her particular cancer. ICAN worked with the pharmaceutical company to expedite the patient's ability to access the drug.

ICAN Practices Experienced and Tenacious Patient Advocacy... We Don't Practice Medicine

ICAN never uses the word "cure" on a disease as complex and multi-faceted as cancer. We aim for the longest life extension possible with the highest achievable quality of life. We will never give up on a patient. There is always something to be done to position a case for the better. ICAN patients and families can have complete confidence that all options are explored as part of ICAN's Personalized Medicine Cancer Case Navigation Programs so that the patient and his/her medical team can make the best possible decisions.



How You Can Help Get Us to the Next Level of Success

To support ICAN's fundraising activities by naming a cancer program in your honor or in another person's honor or memory, please call 602-618-0183 or email fundraising@askican.org

To support ICAN's Remission Coach® search engine project, please call us or email us at remissioncoach@askican.org

To support ICAN by golfing with us at the Liberty Mutual Invitational on Friday, October 17, 2014 at McCormick Ranch Golf Club, please call 602-861-9642 or email golf@askican.org

To support ICAN's Northern California Golf Invitational on Monday, October 13, 2014 at the Napa Valley Country Club in Napa, California, please call 707-591-1131 or email napagolf@askican.org

To join one of our volunteer leadership councils, please call 602-861-3777 or email boardgovernance@askican.org