Philanthropists Carl & Renée Behnke continue a family tradition of supporting lifesaving research at Fred Hutch

WORLD OF GOOD
Thriving oncology partnership to break new ground in Uganda

SAVING EZRA
‘Bubble boy’ cured thanks to newborn screening, transplant

ALCOHOL & CANCER
What’s the real health risk – or benefit?
Dedication drives the discoveries that save lives

DEDICATION RUNS DEEP at Fred Hutch. As you’ll read in this issue of Quest, it can run deep enough among our supporters to span multiple generations, as it has in the Behnke family.

Sally Skinner Behnke’s commitment to improving the Seattle community, and in particular to saving lives by supporting Fred Hutch research, left indelible marks here and throughout the region. Her son and daughter-in-law, Carl and Renée Behnke, continue that family tradition today.

As a board member at Fred Hutch and now as board chair at our treatment arm, Seattle Cancer Care Alliance, Carl has dedicated his time and energy to strengthening our organization so more patients can benefit from our scientific discoveries. And as generous benefactors, he and Renée have helped directly fund discoveries that are improving the lives of patients in our community and around the world.

The $3 million matching challenge the Behnkes have committed for the Hutch Holiday Gala this December perfectly encapsulates the spirit in which they give: making things happen by getting 100 percent involved, and encouraging others to join in, especially when the cause is something that touches us all.

The dedication individuals like you and the Behnkes demonstrate by supporting Fred Hutch’s world-class science makes a difference. Your contributions make breakthroughs happen faster—breakthroughs like blood stem cell transplantation, which is now also saving infants born with severely impaired immune systems. Your partnership inspires our researchers as they transform their own dedication into advances that impact thousands of lives—researchers like virologist Dr. Maxine Linial and the head of our Program in Global Oncology, Dr. Corey Casper, whose work you’ll read about in the following pages.

We are grateful to have a community of supporters who are as passionate as our scientists about fulfilling our mission of ending cancer and related diseases as causes of human suffering and death.

Dr. Mark Groudine
Acting President and Director
Hutch in Uganda

When she was young, Sally Skinner Behnke longed to be a scientist. Instead she carved her own path and turned her childhood dream into a lifelong role as a curestarter, setting in motion a family tradition of supporting transformative science at Fred Hutch. BY SUSAN KEOWN

Seeing in the dark

After a devastating accident in 2010, virologist Dr. Maxine Linial reinvented herself as a blind research pioneer in a sighted world. BY DR. RACHEL TOMPA

Hutch in Uganda

Our writer and photographer return from Kampala with images of the families, physicians, nurses and researchers benefiting from a unique partnership with the Uganda Cancer Institute. BY MARY ENGEL AND ROBERT HOOD

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Women taking certain formulations of birth control pills could face a 50 percent or higher increased risk of breast cancer than those not using oral contraceptives, according to a study by Fred Hutchinson Cancer Research Center scientists published in Cancer Research.

In particular, pills with high doses of estrogen, some types of progestin and certain dosing schedules appeared to boost the risk. However, most women don’t take the high-risk pills, and the study found that low-dose estrogen pills posed no increased risk.

The study, led by Fred Hutch staff scientist Dr. Elisabeth Beaber, was based on the analysis of 20 years of oral contraceptive prescription records from women enrolled in Group Health Cooperative, a Seattle-area health care system. Beaber and colleagues looked at data from 1,102 women aged 20 to 49 who developed breast cancer between 1990 and 2009 and compared their use of oral contraceptives with 21,952 women who remained cancer-free.

The women who had used birth control pills in the previous year had a 50 percent higher risk overall than women who had either never used the drugs or had used them in the past, Beaber said.

Pills containing high-dose estrogen boosted breast cancer risk nearly threefold, and those that contained moderate-dose estrogen increased the chances about 1.6 times, the researchers found.

Women concerned about the link between oral contraceptives and breast cancer should talk to their health care provider and carefully weigh the risks of using oral contraceptives against the benefits they provide, Beaber said, from regulating menstrual cycles to lowering the risk of benign breast conditions.

“Our study results need to be interpreted cautiously,” she said. “This is an important contribution, but it is not yet at the scale where it is … changing any clinical recommendations.”

By JoNel Aleccia

Learn much more about the birth control pills risk online at fredhutch.org/BirthControlRisk
In 2012, the U.S. Preventive Services Task Force concluded that prostate cancer screening provides “very small potential benefit and significant potential harms” and issued guidelines recommending against it. A new study by experts at Fred Hutchinson Cancer Research Center, published in the journal Cancer, explored the impact that stopping prostate-specific antigen (PSA) screening would have on American men.

The researchers used statistical models to predict prostate cancer incidence and related deaths in the U.S. from 2013 to 2025. Their findings indicated that discontinuing PSA screening altogether would result in a 13 to 20 percent increase in prostate cancer mortality (36,000 to 57,000 additional deaths) compared with continuing PSA screening during this period.

“We feel more nuanced guidelines are more appropriate,” said senior co-author Dr. Ruth Etzioni, a Fred Hutch biostatistician. The research showed stopping screening at age 70 may be a better option, reducing the number of men who receive unnecessary treatment while preventing most of the additional deaths associated with discontinued screening.

According to the National Cancer Institute, most prostate cancers diagnosed in the U.S. are found through screening rather than a patient reporting symptoms. Unfortunately, PSA screening is known to lead to large numbers of overdiagnosed cases — situations in which the detected cancer would not cause symptoms or death within a man’s natural lifetime.

“Overdiagnosis causes anxiety for patients and families, imposes an unnecessary economic burden on individuals and misuses health care resources,” said Fred Hutch biostatistician and lead author Roman Gulati. In addition, surgery and radiation deliver a high risk for erectile, urinary and bowel dysfunction. “Treating a cancer that is not destined to grow or present problems cannot improve quality of life for an individual,” Gulati said.

By Joely Johnson Mork

**INFECTION DISEASE**

**Wiping out female malaria-bearing mosquitoes**

**Scientists tweak mosquito DNA to influence production of mostly male offspring**

For many around the world, the drone of mosquitoes isn’t just a nuisance, it signals life-threatening danger: malaria. Spread primarily by a group of mosquitoes known as *Anopheles*, the malaria parasite infects some 200 million people annually and kills more than 600,000, mostly children.

Fred Hutchinson Cancer Research Center and U.K. scientists have developed a technique that could wipe out that disease-carrying bug by engineering male mosquitoes that father mostly male offspring.

Lab tests found the engineered bugs could wipe out mosquito populations in just six generations, or six to 10 weeks. In four out of five tests using cages of non-mutated mosquitoes, introducing the modified bugs crashed the populations, leaving too few females to sustain growth.

This technique, described in *Nature Communications*, potentially could eradicate malaria in a more targeted and environmentally safe way than conventional techniques such as widespread pesticide use and wetland drainage, according to Fred Hutch protein engineer and study collaborator Dr. Barry Stoddard.

“This is not intended to, nor would it ever, wipe out (all) mosquitoes,” he said.

By Dr. Rachel Tompa

**PROSTATE CANCER**

**The paradox of PSA screening for prostate cancer**

**New study forecasts population impact of discontinued testing**

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By Joely Johnson Mork

![Photo by iStock](https://via.placeholder.com/150)

Discontinuing PSA tests entirely would result in a 13 to 20 percent increase in prostate cancer mortality, a Fred Hutch study shows. Elevated PSA can indicate prostate cancer, shown here in red. *Photo courtesy of Experimental Histopathology*
How common is drinking in the U.S.?
Nearly half of adults in the U.S. report being light or moderate drinkers, defined as one drink a day for women, two drinks a day for men. Heavy drinking is anything over that amount, and about 7 percent of U.S. adults fit into this category. About 3 percent of U.S. cancer deaths each year can be attributed to alcohol consumption.

What types of cancer are clearly associated with drinking?
Regular, heavy drinking is associated with an increased risk of oral, throat, larynx, esophagus, liver, breast, colon and rectal cancers. We also know the risk rises with the amount of alcohol consumed.

Should people who are considered at high risk for cancer due to family history be concerned about drinking?
Some studies have found that reducing alcohol consumption may decrease cancer risk among people with a family history of the disease. People with known genetic risk factors should consult their doctor about their alcohol intake.

Is there such a thing as a safe amount of alcohol for people concerned about reducing their cancer risk?
When it comes to drinking and cancer risk, moderation is the key.

Alcohol and cancer risk: Distilling fact from fiction
A conversation with cancer-prevention expert Dr. Polly Newcomb
BY KRISTEN WOODWARD

WHILE MODERATE ALCOHOL intake is consistently associated with a decrease in the risk of cardiovascular disease, the verdict is less clear when it comes to alcohol and cancer risk. Some evidence strongly indicates drinking may increase the risk of certain types of cancer, but other studies suggest it doesn’t adversely impact cancer survival rates. Dr. Polly Newcomb, head of the Cancer Prevention Program at Fred Hutchinson Cancer Research Center, serves up some advice.
Do all types of alcohol pose the same cancer risk?
In general, it’s not the type of alcohol a person drinks but the amount that impacts cancer risk.

What about wine? Is red better than white?
Red wine contains certain compounds, such as resveratrol, which, research suggests, have some anticancer properties. However, my research group found when it comes to increasing breast cancer risk, it makes no difference — red and white wines are equal offenders.

How does alcohol increase the risk of cancer?
In a variety of ways. It increases levels of circulating estrogen, a hormone linked to breast cancer. It also may interfere with the absorption of nutrients such as folate that may protect against cancer. When the body metabolizes the ethanol in alcoholic drinks, it converts it to a toxic chemical called acetaldehyde, a potential carcinogen that has been shown to damage genes and proteins. In addition, the process of fermenting and producing alcohol can introduce various carcinogens into the mix. Heavy drinking also can cause cirrhosis of the liver, which is a risk factor for liver cancer.

How might genetics factor into the alcohol and cancer-risk equation?
Research shows that genes play a role in the metabolism of alcohol, which can influence cancer susceptibility. For example, many people of Asian descent carry a genetic variant that speeds up the conversion of ethanol to toxic acetaldehyde, which can increase the risk of some cancers.

Does tobacco use magnify the cancer-causing effects of alcohol?
Studies indicate that people who both drink and use tobacco are at a significantly higher risk of cancers of the head, neck and esophagus than those who use either substance alone. However, there is little evidence that alcohol further increases the very strong association between smoking and lung cancer.

Any other advice?
Don’t smoke. Maintain a healthy weight. Exercise regularly. Eat a healthy diet. Use sunscreen. Talk to your doctor about cancer screening and getting vaccinated for certain infection-related cancers.

Dr. Polly Newcomb’s research focuses on genetic and lifestyle risk factors, screening and survival of colorectal, breast and other common cancers. Photo by Robert Hood / Fred Hutch
FEATURE

kicking
starting cures

Philanthropists Carl and Renée Behnke continue a family tradition of supporting lifesaving research at Fred Hutch

STORY BY SUSAN KEOWN

WHEN SHE WAS YOUNG, Sally Skinner Behnke longed to be a doctor or a scientist. But she grew up in a time when a girl couldn’t expect that dream to come true.

So Sally carved another path. She turned her childhood wish into a lifelong role as a “curestarter”: kick-starting the cures of the future through support of transformative science at Fred Hutchinson Cancer Research Center.

Sally, who died last year at age 90, built a legacy of philanthropy with Fred Hutch that grew out of her family’s longstanding commitment to local organizations. A reflection of a deep-rooted culture of giving in Seattle, the Behnkes have made major contributions to numerous cultural, medical and educational institutions throughout the region in addition to Fred Hutch.

Today, the Behnkes’ dedication to launching new cures at Fred Hutch continues through Sally’s son and daughter-in-law, Carl and Renée Behnke.

“She’d always say, ‘I wish I could have been a scientist; science was my favorite thing.’ So I think when that opportunity came, to be involved and to see what was going on, she embraced it.”

— Renée Behnke on her mother-in-law, Sally Skinner Behnke
While we probably won’t be able to end all cancer, it seems to me that we’re able to get our hands around it a little bit more. We’re increasing our ability to extend people’s lives with immunotherapy and all of the other innovative things that are coming from the scientists that are here,” Carl said. “So what we’re doing is supporting these great scientists.”

As public funding for research continues to dwindle, the Behnkes and other curestarters are more critical than ever. In partnership with scientists, philanthropists help propel new methods to prevent, detect and treat cancer from Fred Hutch laboratories to patients through the center’s treatment arm, Seattle Cancer Care Alliance.

“A lot of things are being taken from the lab and being turned into products, in some cases becoming the standard of care, and a lot of that stuff is hard to fund,” said Dr. Eric Holland, director of Fred Hutch’s Human Biology Division, the Alvord Brain Tumor Center at the University of Washington, and the Solid Tumor Translational Research effort.

Holland’s STTR group, which connects researchers and clinicians at Fred Hutch, SCCA, UW Medicine and Seattle Children’s, is dedicated to strengthening the cycle of discovery by which advances developed in the lab are delivered to the patients who need them.

Like mother, like son

The Behnke family knows the devastation of losing loved ones to disease. “Every single person — no matter who you are, what level you are financially, emotionally — you have somebody in your family who’s been touched by cancer,” said Renée, who lost her sister, Laurel, to bladder cancer last year.

In 1988, after more than a decade as a Fred Hutch benefactor, Sally’s relationship with the center was just beginning to deepen when her brother, prominent businessman Ned Skinner, died of pancreatic cancer. The following year, her son, Ned Behnke, a well-known Seattle artist, died of AIDS at age 40.

Carl and Renée believe those painful losses may have inspired Sally’s unshakeable commitment to Fred Hutch. From her founding membership on the board of the Fred Hutch Foundation in 1987 to her chairmanship of that board and leadership roles in several capital campaigns, Sally gave of herself in many ways to Fred Hutch over her lifetime.

“Sally was a force of nature. When she got involved in something, she made things happen,” said Peter Horvitz, Sally’s former neighbor who has served with Carl for years on boards at Fred Hutch and the Pacific Northwest Ballet. “She instilled that into her kids. Carl, in many ways, is following in her footsteps.”

Sally began to build a bridge between Fred Hutch and the next generation of Behnkes in 1993, when her family liquidated the corporation where Carl had served as president and director, putting him out of a job. At the time, Fred Hutch leadership was planning a campaign to build a home for Fred Hutch’s Clinical Research Division.

“So my mother chimed in,” remembers Carl with a laugh, ‘Well, my son is unemployed — he can lead the capital campaign!’” Carl stepped up to the challenge, and the E. Donnall Thomas Clinical Research Laboratory Building was completed in 1997.

That campaign kicked off decades of involvement for Carl. He has since served on several committees and boards, including two years as chair of the Fred Hutch board of trustees. During his membership on that board, he helped with the formation, in 1998, of SCCA. In 2006 Carl joined the SCCA board, and this July he began his term as SCCA’s board chair.

Today, Carl says he finds a deep satisfaction in knowing that the work he and his fellow SCCA board members have done has helped shape an organization with the highest five-year survival rates in the nation for many common cancers. And because SCCA serves as the gateway through which treatments discovered and perfected at Fred Hutch are introduced to patients across the globe, he says this work has extended his family’s tradition of helping the community to places far beyond Seattle.

“Instilled in me by my parents was the importance of contributing to make the community better,” Carl said. “Fred Hutch, in fighting cancer, goes beyond that because the therapies they develop go around the world.”
Powerful giving: The most generous cities

An analysis by one of the industry's largest trackers of charitable giving shows Seattle leading among 285 U.S. cities in online charitable giving based on per capita donations. While the report does not reflect all charitable giving, the growth in online donations illustrates the power of this type of private philanthropy, which totaled more than $822 million from 8.3 million donations in 2013.

Average donation
Top 50 giving cities online donations per 1,000 residents

<table>
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<th>Rank</th>
<th>City</th>
<th>Donation per 1,000</th>
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<td>Arlington, Va.</td>
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<td>Cincinnati</td>
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<td>Bellevue, Wash.</td>
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<td>10</td>
<td>San Francisco</td>
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11. Minneapolis
12. St. Louis
17. Pittsburgh
18. Austin, Texas
19. Stamford, Conn.
20. Orlando, Fla.
21. Salt Lake City
22. Miami
25. Denver
26. Plano, Texas
27. Ft. Lauderdale, Fla.
28. Irvine, Calif.
29. Richmond, Va.
30. Raleigh, N.C.
31. Cary, N.C.
32. Sunnyvale, Calif.
33. Tampa, Fla.
34. Houston
35. Dallas
36. Madison, Wis.
37. Portland, Ore.
38. Rochester, N.Y.
39. Durham, N.C.
40. Boston
41. Columbia, S.C.
42. Richardson, Texas
43. Santa Clara, Calif.
44. Chicago
45. Charlotte, N.C.
46. Knoxville, Tenn.
47. Grand Rapids, Mich.
48. San Diego
49. Baltimore
50. Oakland, Calif.

Online giving demographics
Taking median income and population into account, Seattle still continues to shine in online giving based on 2013 data.

Total online donations

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<th>Rank</th>
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<th>Population Rank</th>
<th>Total Online Donations</th>
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<td>Chicago</td>
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<td>Houston</td>
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<td>$177,214</td>
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Rank in online giving by percent of median income

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<td>6</td>
<td>Miami</td>
<td>0.069%</td>
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<tr>
<td>7</td>
<td>Washington, D.C.</td>
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<td>8</td>
<td>Alexandria, Va.</td>
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<tr>
<td>9</td>
<td>Minneapolis</td>
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<tr>
<td>10</td>
<td>Pittsburgh</td>
<td>0.054%</td>
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Percent of population making an online donation

<table>
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<th>City</th>
<th>Percent of Population Making an Online Donation</th>
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<td>Ann Arbor, Mich.</td>
<td>33.80%</td>
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<td>3</td>
<td>Cambridge, Mass.</td>
<td>33.87%</td>
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<td>4</td>
<td>Arlington, Va.</td>
<td>33.35%</td>
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<td>5</td>
<td>Durham, N.C.</td>
<td>32.87%</td>
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<td>6</td>
<td>Seattle</td>
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<td>7</td>
<td>Atlanta</td>
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<td>8</td>
<td>Cary, N.C.</td>
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<td>9</td>
<td>St. Louis</td>
<td>29.81%</td>
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<tr>
<td>10</td>
<td>Cincinnati</td>
<td>29.88%</td>
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Sources: Blackbaud and Evaluating Effectiveness Most Generous Online Cities' report.
Bringing innovation from the lab to patients’ bedsides takes commitment — not just from scientists, but also from the benefactors who share their vision.

Dr. Sunil Hingorani has used private funding to translate treatments developed in his lab at Fred Hutch into clinical trials for patients with pancreatic cancer. Hingorani developed an enzyme-based therapy that knocks down walls of tissue shielding pancreatic cancer from antitumor drugs. The enzyme leaves the tumor vulnerable to drugs that slip through its crumbling defenses. Results of this combination therapy were promising in early trials, and Hingorani has now launched two larger trials that are recruiting patients throughout the country.

“Those of us who take care of patients with pancreas cancer are always hesitant to use too much hyperbole. We have been humbled many times by this cancer,” said Hingorani in an interview last year. “However, I can tell you from our standpoint this provides a new way to understand why the tumor has been so resistant to therapy, and this new treatment may therefore represent a game changer.”

Carl’s role at SCCA today brings his family’s involvement full-circle: Decades ago, Sally, as a third-generation board member and board chair at Seattle Children’s, helped lay groundwork by cultivating deeper collaboration between Children’s and the UW; today, Children’s and UW Medicine co-own SCCA along with Fred Hutch.

“The Behnke family’s two generations of generosity in time and wisdom to Fred Hutch and SCCA has been critical in helping us become the institutions we are today,” said Dr. Fred Appelbaum, deputy director and executive vice president at Fred Hutch and executive director and president of SCCA. “Their commitment to innovation, quality and ultimately patient outcomes continues to shape our organization and has a profound effect on the care our patients receive. The Behnke family is a wonderful example of how leadership can make our world a better place.”

Rising to the challenge

This year, the Behnkes have taken their partnership with Fred Hutch a big step further. For the 2014 Hutch Holiday Gala, they’ve issued a $3 million challenge that will support the transformation of benchside research into bedside cures for a range of cancers, from malignancies of the brain and pancreas to the rare, diverse cancers collectively known as sarcomas (see sidebar).

This challenge illustrates Carl and Renée’s dedication to causes they believe in, said their friend Horvitz. “If they are going to be involved in something, they’re really involved, they’re very supportive. They are doers. They make things happen. With their newest $3 million gift as a challenge for the Gala, that’s a huge statement about their commitment,” he said.

The commitment of curestarters like the Behnkes is particularly important for translational research since many aspects of the process can be difficult, if
With the help of private support, Dr. Hans-Peter Kiem has developed an innovative gene therapy for glioblastoma, an aggressive brain cancer, and brought it into a clinical trial at SCCA. His therapy uses a harmless virus to carry a protective gene to blood stem cells. With this armor, the blood cells become resistant to chemotherapy, while the brain cancer remains vulnerable — allowing patients to receive more effective doses of chemotherapy than they would otherwise be able to tolerate. Results of Kiem’s early-stage clinical trial in seven patients, published this summer, show that this therapy helps patients survive longer.

“I think this is very promising,” said Kiem in an interview upon the release of the results. He and his collaborators are now gearing up for a larger trial of their pioneering therapy.

“You can’t write an NIH grant to do this. This is the kind of thing we need help from private philanthropy to do,” Holland said.

Although efforts like HIDRA aren’t easy, Holland added, “if you have to really be challenged to do something difficult, in some ways you’re ahead of everybody once you achieve the goal.”

Like Holland, Carl and Renée embrace a good challenge. Whether building successful businesses, as they both have; tending the enormous garden of roses, vegetables and herbs at their home; or fueling advances that will lead to cures for many cancers within their children’s lifetimes, if not their own, the Behnkes are doing the difficult work it takes to grow something better for the future. The fruits of their labor are now rising from a seed sown many years ago by a woman, now a memory, who was once a little girl with a dream.

Private funds raised with the help of the Behnkes’ Gala challenge could also advance the development of vital translational research resources, Holland said. He named the Hutch Integrated Data Repository and Archive as an example. HIDRA, which will launch with a pilot this year, is a massive database combining patient health data with molecular profiles of tumors. Ultimately, HIDRA will serve as a tool for doctors to find the best treatments for each patient’s unique disease.

“Without support from donors, we would not have been able to develop the methods for generating sarcoma-specific T cells or taken this treatment into the clinic,” Pollack said. Philanthropic support was a major boost, he added: “We have been able to take the data generated as a result of private support and use it to successfully apply for new grants.”

In an ongoing SCCA clinical trial that sprung out of privately supported research, Dr. Seth Pollack is raising a formidable force of immune cells to target sarcoma. Pollack, a Fred Hutch scientist who sees patients at SCCA, multiplies sarcoma-targeting immune cells by the billions in the lab and gives them back to patients to attack their tumors en masse. Initial results have been encouraging, and Pollack is currently working on refining his treatment to make the next iteration more effective.

“You can’t write an NIH grant to do this. This is the kind of thing we need help from private philanthropy to do,” Holland said.

Although efforts like HIDRA aren’t easy, Holland added, “if you have to really be challenged to do something difficult, in some ways you’re ahead of everybody once you achieve the goal.”

Like Holland, Carl and Renée embrace a good challenge. Whether building successful businesses, as they both have; tending the enormous garden of roses, vegetables and herbs at their home; or fueling advances that will lead to cures for many cancers within their children’s lifetimes, if not their own, the Behnkes are doing the difficult work it takes to grow something better for the future. The fruits of their labor are now rising from a seed sown many years ago by a woman, now a memory, who was once a little girl with a dream.

Write to Susan Keown at skeown@fredhutch.org
How to see in the dark

After a car accident left her blind, Fred Hutch virologist Dr. Maxine Linial learned to lead her research team and continue pioneering work in the lab without sight

BY DR. RACHEL TOMPA

FROM HER BED in the convalescent home, Dr. Maxine Linial kept asking for her glasses.

She knew she’d been badly injured after being hit by a car and couldn’t see, but she was sure that she just needed her glasses. Repeatedly, she’d put them on only to find it made no difference, and her son, Ross, would remind her that she was now blind.

“I would say, ‘I can’t be blind, that can’t be right,’” Linial said. “But I was blind.”

At first, the virologist could see shadows and some gray blobs. But soon, that limited vision faded to black, and in the four years since, Linial has had to reinvent herself to live as a blind scientist in a sighted world.

CONTINUED >
One of Fred Hutchinson Cancer Research Center’s longest-serving faculty members, Linial, 70, is no stranger to forging her own way. She was Fred Hutch’s first laboratory-based faculty member, and for years she was the only female faculty member of what is now the Basic Sciences Division.

“I love Frank Sinatra, and especially his song ‘My Way,’” Linial said. “That’s my song. I did it my way.”

Linial has since paved the way for future women scientists. Many of Fred Hutch’s female faculty say they owe their start to Linial’s mentoring. Now she relies on her tight network of friends and colleagues to support her as she continues to lead her team, and her research field, without sight.

When she describes the research in her laboratory, Linial’s hands encircle a phantom petri dish in front of her. Her fingers flick at imaginary cells as she explains how foamy viruses, which she has studied for more than two decades, got their name: When the viruses infect cells in a dish, they kill so dramatically the cells look like they’re foaming.

Linial misses seeing those dying cells in real life. As a virologist specializing in the molecular ins and outs of foamy viruses, she got used to staring through a microscope for hours on end, examining what the cells looked like, what infections looked like. Her area of research relies on a particular laboratory technique that turns infected cells blue, and Linial specialized in counting hundreds or thousands of the blue cells under a microscope.

“Nobody else liked counting blue cells, but I liked counting blue cells,” Linial said. Now, people in her lab gripe when they have to do these experiments, she said, “and I say, ‘Oh, I wish I could count the blue cells!’”

“So much of the type of work that Maxine and I do is visual,” said Dr. Denise Galloway, Linial’s longtime friend and virology colleague at Fred Hutch.

“To have [experiments] just described to you without actually seeing the data — it’s amazing to me that she can interpret that and make sense of that.”

‘I STILL HAVE THINGS TO OFFER’

In March of 2010, everything changed for Linial. She had left her house for a morning run when a driver ran a red light and crashed into her in a crosswalk.

Over the next 10 months, she slowly recovered from the major injuries she suffered — all but one. The optic nerve that conveyed information from her eyes to her brain was damaged and she was left in darkness. No longer able to pursue the hobbies that used to fill her time — hiking, gardening, cooking, running half marathons — Linial threw herself into her research.

Although Linial says she thinks of the time before the accident as her “real life,” she can still be a scientist, and she is dedicated to the place where she’s nurtured her career over the past four decades.

“I guess I could say, ‘Well I can’t see anything and I should just slip out of science,’ but I think I still have things to offer,” she said. “I’m totally devastated by being blind, but coming to the Hutch and doing what I can is very important to me.”

STUDYING THE WHAT-IFS

Linial began studying foamy viruses in the early 1990s, a nearly solo venture, and she continues to be a leader in the field. Foamy viruses are a retrovirus, the family of viruses that includes HIV, and although they are prodigious killers of cells that grow in petri dishes, there is no evidence they cause disease in humans or other animals.

Linial studies these viruses in part because of the what-ifs. Nobody had studied HIV or its close relatives until the virus mutated enough to jump from chimpanzees to humans and trigger the AIDS pandemic — Linial wants to get a head start in case foamy viruses make a similar leap.

As she continues to lead her scientific field, Linial is happy to know that her work advocating for women in science has paid off.

“I think what I did was helpful, because the Hutch has a lot of women now,” she said. “So I hope that I have created a good legacy here at the Hutch. But now I can sit back and let other people do some of these things.”

Write to Rachel Tompa at rtompa@fredhutch.org
TOP: On a visit to the Uganda Cancer Institute, Ronald Lumala cuddled his 4-year-old son, Mike Kiragga, who was successfully treated for Burkitt lymphoma.

ABOVE: Dr. Nixon Niyonzima, who is working on a doctorate in molecular and cellular biology at Fred Hutch, filled in at the UCI this summer on a visit home to Kampala.

ABOVE RIGHT: Fred Hutch’s Dr. Corey Casper and UCI’s Dr. Jackson Orem, co-directors of the Uganda Cancer Institute/Hutchinson Center Cancer Alliance, shared a celebratory moment on the roof of the almost-completed research, training and outpatient facility.

RIGHT: A passionate believer in education, UCI head nurse Allen Naamala Mayanja is always looking for training opportunities for her staff to advance in their careers, going from the yellow belts worn by junior nurses to red to her own black belt.
Over the last decade, Fred Hutchinson Cancer Research Center and the Uganda Cancer Institute have been building a unique international partnership. Now the partners are about to have a new home.

A three-story, state-of-the-art research, training and outpatient facility is slated to open in early 2015. With a red-brick exterior that matches the bricks on Fred Hutch’s campus, it rises on the edge of the UCI’s Kampala campus, next to a hodgepodge of stucco-walled structures that have served as Uganda’s only cancer treatment center for more than 40 years.

In advance of the building’s opening, Hutch photographer Robert Hood and writer Mary Engel went to Kampala to see the partnership’s progress to date.

The accomplishments are many. Just look at Mike Kiragga, a bright-eyed 4-year-old boy cured of Burkitt lymphoma, the most common childhood cancer in sub-Saharan Africa. A Fred Hutch-UCI team introduced a systematic approach to treating this cancer that has nearly doubled survival rates and is now being applied to other cancers.

More than a dozen Ugandan physicians have trained at Fred Hutch and returned to practice at the UCI, and another 200 individuals have undergone shorter trainings in Kampala. Almost 30 joint research projects are completed or ongoing.

With the opening of the outpatient facility, as well as a recently completed inpatient hospital built by the Ugandan government, physician-researchers like Dr. Nixon Niyonzima, now studying at Fred Hutch, will have top-notch labs and a community of scientists to go home to.

“The trainees can now say, ‘This is a place I can practice,’” said Dr. Corey Casper, head of the Hutch’s Program in Global Oncology. “I can say to them, ‘There will be a future where you can practice medicine the way you want to.’”

Write to Mary Engel at mengel@fredhutch.org and Robert Hood at rhood@fredhutch.org
‘It was either this or he doesn’t live’

Transplant saves first ‘bubble boy’ in Wash. state detected with newborn screening

BY JONEL ALECCIA

IN THE NINE MONTHS since Washington state started screening newborns for the disorder commonly known as “bubble boy disease,” hospitals have tested more than 50,000 babies for the rare condition that leaves victims at the mercy of common germs.

So far, just one child has turned up positive.

Ezra Dixon, born April 7, appeared to be a healthy baby — until the blood test revealed he had none of the T cells that protect the body from infection, a certain sign of severe combined immunodeficiency, or SCID.

But because Ezra’s condition was caught early, before he developed a life-threatening illness caused by his impaired immune system, the bald, blue-eyed boy was able to receive a bone marrow transplant when he was just 2 months old.

Within two weeks, healthy cells from his toddler brother, Judah, had taken hold, offering Ezra a promising future — and underscoring the results of a new study involving doctors at Fred Hutchinson Cancer Research Center and Seattle Children’s.

“It was either this or he doesn’t live,” said Rachel Dixon, 24, Ezra’s mom.

She and her husband, Zach Dixon, 25, both from Spokane, Washington, were shocked when they learned their 3-day-old baby had a potentially fatal disease.

“The most I’d ever known about immune deficiency was what I’d seen on ‘House,’” recalled Rachel Dixon. “We spent a couple of days thinking we’d have a ‘bubble boy’ for the rest of our lives.”

But the shock turned to relief when doctors told the Dixons their baby could be cured with a bone marrow transplant, a procedure pioneered by Fred Hutch researchers that has been used to help more than 1 million people worldwide.

Recent research published in The New England Journal of Medicine confirmed what specialists have long believed: Children with SCID can be cured with stem cell transplants, but early treatment is key.

“If you are transplanted at less than 3 months of age, you have a 94 percent chance of survival,” said Dr. Suzanne Skoda-Smith, clinical director for the Division of Immunology at Seattle Children’s.

Skoda-Smith and her colleague Dr. Lauri Burroughs, an assistant member in the Clinical Research Division at Fred Hutch who focuses on pediatric stem cell transplantation, were among researchers who provided groundbreaking data from 240 babies with SCID who received transplants at 25 centers from 2000 to 2009.

By contrast, survival was only 50 percent among babies older than 3 ½ months and who had infections at the time of transplant.

The study emphasized the need for screening for SCID, which affects about one in 50,000 babies. Today, 31 states either screen for the condition or have plans to start this year. Three more states have agreed to screen but don’t have a timetable to start, according to the Immune Deficiency Foundation.

But at least 16 states still have no plans to screen babies like Ezra. Without screening, SCID is typically detected only when a child gets a life-threatening infection, usually at 4 to 6 months of age.

More than 50 days after his transplant, Ezra was doing well, his mother said. But she worries about other families who don’t have the benefit of early detection and treatment.

“This is something that you can’t know about until something goes wrong,” she said.

Write to JoNel Aleccia at jaleccia@fredhutch.org
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The Williams Family / Fred Hutch File
Nearly 1,000 riders covered 60,000 miles Aug. 8-10 to help end cancer by participating in Obliteride, the second annual bicycling and fundraising event. Many wrote the names of loved ones in whose honor or memory they were riding on their bike flags, jerseys and even arms and legs as a poignant reminder of the true reach of cancer. The efforts of the riders, as well as the 600 volunteers who supported them, have generated over $1.7 million to date for cancer research at Fred Hutch. Fundraising continues through Sept. 30.

Musician Michael Franti helped kick off Obliteride weekend with a rousing performance.