INTERVIEW

Marcia K. Horn speaks to Alina Dietrich on the upcoming World Epigenetics Summit
July 26th - 28th 2011
Boston, MA

Marcia K. Horn is President and CEO of the International Cancer Advocacy Network (ICAN), a cancer patient advocacy organization and tax-exempt charity headquartered in Phoenix, Arizona:

What is the International Cancer Advocacy Network or ICAN's mission in the cancer patient advocacy arena?

ICAN's twin goals are extended survival and the highest possible quality of life for Stage IV cancer patients. ICAN's niche is Stage IV patients who—in the patients' view and ours—have been prematurely written off by their medical teams. At the patient's request, we equip them with new world class oncology teams wherever they reside or wherever they are willing to travel. Coming to us almost entirely through word-of-mouth referrals, our patients hail from all 50 states and 36 countries to date, and we expect to be working with our 8000th patient sometime in the first quarter of 2012. Sometimes we find that we're dealing with 5th generation referrals in terms of the new patient's relationship to the original patient of many years ago. We outline new strategic options, research relevant clinical trials based on their specific patient profile, and investigate compassionate release of experimental agents outside the context of clinical trials. We are forever dealing with the specifics of a patient's case, down to the very minutiae that might make a difference to treatment plans that otherwise appeared appropriate.

We live and breathe personalized medicine, advocating detail-by-detail cancer case management based on all possible profiling technologies, and have been doing so since long before the term "personalized medicine" came into vogue. We're continually dealing with H and E, IHC studies, FISH, sequencing and NGS, molecular cytogenetics and mRNA/gene expression profiling, fusion gene microarrays, and chemoresistance and chemosensitivity issues in the reports and literature that we review, and in the emails we send explaining all this to our staff/research volunteer corps as well as the patients we have who want to understand everything about their disease. We're learning more about areas such as SNP detection and immunoprecipitation/RIP-ChIP. We have a network of research oncologists and laboratory scientists from around the country who we view as the "great explainers" who clarify for us in detail how their world of novel diagnostics and cutting-edge therapeutics impacts our world of Stage IV cancer patients.

Immersing ourselves in gene expression profiling and functional tumor profiling reports, we work with specialty labs across the country and lament that there are still not enough oncologists ordering

"Our patients hail from all 50 states and 36 countries to date, and we expect to be working with our 8000th patient sometime in the first quarter of 2012."

these reports. With the impressive results we've seen attributable to the pathbreaking laboratory technology platform at Rational Therapeutics in Long Beach, California in terms of impact on life extension with high quality of life of some of our patient referrals, we wonder why the insurance industry isn't beating a path to Rational Therapeutics' door and mandating RT chemosensitivity and chemoresistance assays for cancer patients as a matter of course. Sadly, we are finding there is still quite a bit of eye-rolling cynicism about the reports issued by these specialty labs, and we have to work very hard to arm the patient with compelling arguments that will alert the oncologist to the importance of these reports—whether molecular profiling or the kind of functional tumor profiling assays which the brilliant Robert A. Nagourney, M.D. at Rational Therapeutics has so effectively pioneered.

"We're dealing perennially with desperate Stage IV patients, the Oncologic Sword of Damocles, and their distraught families."

We also encourage the patient to insist on having the oncologist go line-by-line and explain the results that come in (and when they don't or won't, we'll do the explaining). We think these profiling results and their relationship to the drug pipeline now or in the future are critical to understand, so we make sure that we have that very important conversation with the patient even if the oncology team thinks it's not relevant to "the here and now" of treatment. Our advocacy services are customized, with an eye to strategic planning several moves ahead at all times. We have back-up plans for the back-up plans if a patient's imaging "goes south" and certain options end up being foreclosed (a trial unexpectedly has full accrual or the patient's profile jettisons him from clinical trials consideration altogether).

We're thus not patting a patient on the head and saying "here's our colon cancer brochure" or "here is the time your support group meets" or "here are 20 oncology practices for you to call on your own until you find your new oncologist." No, to us cancer patient advocacy is a moral imperative. We're dealing perennially with desperate Stage IV patients, the Oncologic Sword of Damocles, and their distraught families. In our typically two hour initial phone interviews reviewing the case for the first time with the patient, it is not unusual for the patient to be sobbing throughout saying "this is the first time in months (or ever) that I have been given any hope." And that means by anyone, whether oncologist or other cancer organization. And that also means concrete hope, not false hope. So we don't make emotionally distraught patients play phone tag with unresponsive or dilatory "Patient Hotlines." We pinpoint exactly the surgical oncologist, medical oncologist, radiation oncologist, interventional radiologist, or anesthesiologist who they should see based on the overarching and specific details of their case. Over the past 15 years we have come to know superb oncologists—not only at the comprehensive cancer center level but at the rural oncology level where unsung heroes practice in abundance without the press office *accoutrements* of the major cancer centers. And we are adding to that network of oncologists every single day.

At ICAN, through our Remission Coach[SM] programs, we are working with the patient throughout the

course of every decision point and every fork in the road, making sure that they have the most relevant cutting-edge information and are fully empowered to make the most informed decisions possible, in consultation with their teams. The psychic pay-off for us is when patients receive a "bravo" for the level of detail and sophistication that ICAN brought to bear on the patient questions we composed for the initial consultation (as recently happened at Sloan-Kettering and a rural California oncologist's office a couple of hours apart on the same day). Some of the patients we deal with are extremely sophisticated and come to us with as many as seven comprehensive cancer center opinions under their belt which can mean up to nine or more separate medical opinions. We sort through those opinions to make sure the patient has everything needed to make informed decisions at critical junctures. Maybe the most relevant trial for that patient is not at any of the seven centers recommended in the opinions, but at another leading cancer center, for example, the University of Alabama at Birmingham, and we'll tell the patient why that's the most promising or viable course to take compared to all the other options. It will always be the patient's ultimate decision, consulting with the lead oncologists and principal investigators involved. We are not practicing medicine, but based on the feedback we receive from patients, their families, and medical teams, we are unapologetically dispensing the most robust cancer advocacy services anywhere. The fact that we have arrived at the choking point of patient waiting lists (we simply don't have the staff or resources to keep up with not only new patient demand but with the caseload of our existing patients by virtue of their extended survival) underscores the importance of what we're doing to extend life.

"We are unapologetically dispensing the most robust cancer advocacy services anywhere."

How did you personally get involved in cancer advocacy? I understand you graduated in Political Science from Stanford and went on to Stanford Law School graduating in 1980. How did a practicing commercial litigator and appellate lawyer end up dealing with cancer patients 15 years ago when ICAN was founded?

Our Founding Chairman is Sidney Rosen, a noted international lawyer and community leader in Phoenix, Arizona. Sid's beloved wife Babette was my best friend and comrade-in-arms when we worked together on *pro bono* immigration cases for citizens of the former USSR in 1990-1992. She was diagnosed with a very challenging head and neck cancer in 1992. Instantly, Sid put his legal practice on hold and transformed himself into the ultimate patient advocate. He would see Babette's diagnostic imaging and would receive personal primers from the radiologist who was reviewing the scans before the radiologist's report was even typed up and sent to the oncology team. To this day, you can walk the corridors of the comprehensive cancer centers where Babette was treated, and the staff will remember Sid Rosen with awe and affection. Sid camped out with Babette in hospital and chemo rooms throughout 46 rounds of chemo, two ear-to-ear laryngeal resections, plus countless rounds of radiation (and ultimately whole-brain radiation) and enlisted me to help him chase down every lead and every promising

"The premise of ICAN is that if a patient or patient family doesn't have a "Sid Rosen" personally in tow who will push the envelope at every opportunity, they would have the best in cancer patient advocacy at ICAN..."

experimental drug that had even a hint of activity against squamous cell carcinoma of the head and neck. Sid even ended up garnering the support of over 25 United States senators for the compassionate use of an experimental drug whose developmental sponsor was the National Cancer Institute—that was and remains a first, believe me. NCI officials said they had never seen anything like what Sid had single-handedly accomplished. Despite those Herculean efforts, on March 13, 1996, Babette passed after a 5-year battle in which she had given new meaning to the word "valiant." She was an angel on this earth who fought cancer with complete empowerment and resolve.

ICAN is thus a tribute to Babette and the millions of patients worldwide braving and living with this disease every hour of every day. Sid, as Founding Chairman, along with one of our Founding Trustees Carol Ginsberg, asked me to sign on as executive director in 1997; by June of 1999, my role and responsibilities had extended to President and CEO. The premise of ICAN is that if a patient or patient family doesn't have a "Sid Rosen" personally in tow who will push the envelope at every opportunity in an effort not to miss anything, they would have the best in cancer patient advocacy at ICAN—an organization that makes their case paramount throughout their battle for life.

What did you find different in transitioning from an attorney's role to a patient advocate's role?

The same skill set developed as a lawyer—and I trained with the best in Dan Durrant, Bill Hawgood, and Ronald Jay Cohen—applies with equal force in the cancer patient advocacy world: the ability to recruit the perfect expert witness requires the same skill set that we use in connecting the cancer patient to the best possible medical team. The only difference is that an expert witness who may testify at a trial years later needs to have the ability to charm or hopefully bond with the judge and/or jury. In the oncology arena, when we recommend that a patient see a particular oncologist, we're going strictly for the oncologist's brain power and fluency in the pipeline. Bedside manner, in other words, is an extra gift and a pleasant surprise when we do see it and certainly not the reason we're connecting a patient with a certain physician. Other skills—such as the ability to persuade through oral and written communication—are used every hour at ICAN. The appellate lawyer's attention to detail and mastery of a trial record is the same skill used in mastering the patient's record or understanding all the drug options for a particular case based on the analysis of peer-reviewed literature and the clinical trials pipeline. The only difference is that the trial record is frozen in place and static, while the patient's case is ever-changing, and so every hour at ICAN is completely different from the previous hour in terms of the gamut of issues we're dealing with. Since the entire field of cancer research and cancer treatment is daunting in its scope, we frequently say to a patient: "We don't know, but we will find out." That just happened when we found out that the delay in getting lab results sent to the patient's oncologist came down to an issue of the lab being "unable to extract DNA" from what had been an ample core biopsy sample. We're getting to the bottom

"I think most researchers and oncologists would agree that the ALK inhibition area has been a game-changer over the past year."

of this unusual issue right now in terms of what went wrong and why, since since these lab results will influence the treatment plan.

Some days, ICAN headquarters resembles the White House Situation Room. In the many thousands of patient cases we have handled since our founding, no two patients even within the same cancer subtype have demonstrated as many similarities as they have differences. That "every patient is unique" philosophy squares well with our abiding interest in anticancer drug discovery, biomarker discovery and application, as well as the fields of genomics, proteomics, chemo-genomics, pharmacogenomics, metabolomics, epigenomics, and epigenetics.

Personally, what was it like to go from the social sciences and the legal profession into total immersion into the cases and medical problems of advanced cancer patients?

When I was at Stanford, I didn't go near the hard sciences. I guess I was panicked that if I did, I'd never get admitted to graduate school. So my Stanford science requirement was satisfied by *Physics for Poets* and *Extraterrestrial Civilizations* along with a summer course at UCLA in astronomy. Now, given total immersion in the war on cancer and the drug pipeline, I relish each and every day what I had been terrified of decades ago. Thanks to the recommendations of two of my mentors, Dr. Bob Pettit, Chairman of ICAN's Scientific Advisory Council, and Daniel Von Hoff, M.D. of TGen, I have been an active Affiliate Member of ASCO since 2007 and am fueled by taking CME courses (just passed a mantle cell lymphoma therapeutics course last weekend). Dr. Von Hoff, in a slip of the tongue during a seminar recess several years ago introduced me to a colleague as "Dr. Horn." I felt like a groupie being smiled at by a rock star—what a thrill. By the way, Dr. Von Hoff's famous phrase "the context of vulnerability" which I mention at least once a day to some patient somewhere in the world is also relevant to the epigenetics arena, as we are always looking for the context of vulnerability in a patient's specific tumor or molecular profile. Since our role in a patient's battle can be pivotal, we are all wired here at ICAN as workaholics, with 100-hour weeks being the norm, but we all think that it is exhilarating (even if it's exhausting) to be making such a difference in people's lives.

Has there been a big issue in personalized medicine that has impacted your patient cases?

Yes, absolutely. I think that most researchers and oncologists would agree that the ALK inhibition area has been a game-changer over the past year. When the PF2341066/crizotinib clinical trial results and the importance of the EML4-ALK fusion gene were announced June, 2010 at ASCO, we were emailing the principal investigator Alice T. Shaw, MD, PhD at Mass General and talking to the medical genetics folks at Pfizer within days, seeking practical guidance on labs with validated fusion gene testing.

ALK testing has been a top priority in our NSCLC Programs. We're extremely concerned, though, that mainstream oncology has been embarrassingly slow in understanding the importance of sending resected tissue to determine

EML4-ALK fusions, especially when it is apparent from the EGFR-negative/KRAS-negative result that confirmation of ALK needs to be prioritized for trial enrollment. There is every indication that crizotinib as well as TAE684 and other ALK inhibitors in development are going to dramatically impact cancer therapeutics for hundreds of thousands of lung cancer and blood cancer patients worldwide. Xianming Deng's group in Molecular Pharmacology at Harvard, which just last month identified and synthesized 3,5-diamino-1,2,4-traizole urea analogues as promising ALK inhibitors, has made an important contribution not only to our NSCLC patients down the road but to our DLBCL (diffuse large B cell lymphoma), ALCL (anaplastic large cell lymphoma), and SCC (squamous cell carcinoma) patients. Because of the significance of the Deng group's work, I was able to send an email outlining the prospect of ALK inhibition for DLBCL patients in years to come to the family of someone who had just been diagnosed with DLBCL and who had decided not to pursue any treatment against the advice of his medical team. Hopefully the email I sent will cause this particular patient to reconsider, but his decision regarding treatment or no treatment is obviously sacrosanct. We will continue to follow the discovery and development of small-molecule ALK inhibitors closely through the *Nancy Strauss Hematological Cancer Advocacy Program* at ICAN.

"It's the small number of companies where the alleged hotlines often lie dormant that remain most vexing to us."

What's the interaction between ICAN and pharmaceutical and biotech companies and between ICAN and the research world?

There is quite a bit of interaction at a host of different levels. We get gut reactions at ICAN based on the level of responsiveness of principal investigators and pharmas or biotechs as to what compounds will go the whole distance to FDA approval. When you have scintillatingly brilliant PIs like Alice Shaw, MD, PhD who answer your extremely detailed ALK questions and delightfully responsive pharma executives such as Dr. Rob Sweetman of Pfizer Oncology who was emailing me a second detailed response when the doors of his plane were closing, you know you are dealing with a team that truly cares about cancer patients and the compound they're working with in clinical trials. It's the small number of companies where the alleged hotlines often lie dormant that remain most vexing to us. I don't have words of sufficient excoriation for the times when our queries involve the dramatic and well-considered request for compassionate release of an experimental drug via Single Patient IND/Emergency Use, resulting nevertheless in the patient getting the brush-off.

To counter such insensitivity, we have been developing our own network of researchers across the country who are responsive and collegial. We call this internally as "meeting the Yu-Wen Standard." Yu-Wen Zhang is an investigator at Van Andel in Michigan who I corresponded with on MIG-6 because we had a gallbladder case with an NSCLC primary in her past, and MIG-6 deficiency (perhaps

either via mutation in MIG-6 or not expressed) is implicated in both cancers. In addition to offering to look for mutations in the MIG-6 gene, Yu-Wen offered to test the archived tissue of the NSCLC resection and the more recent gallbladder tissue via staining for c-MET protein expression to determine if a MET drug would be beneficial. We've never forgotten that kind of rapid-reaction, gracious, and collegial response, where primacy was placed on the impact of research on the patient's therapeutic roadmap. That's the constructive attitude that we look for in dealing with researchers and oncologists worldwide.

"We're firm believers in a strong FDA as well as iron-clad patent protections for both inventors of compounds and the pharmaceutical and biotech industries."

ICAN seems to have an interest in lobbying and legislative activity and has an active interest in the discovery and development of anticancer compounds through your Scientific Advisory Council. What is your involvement in that?

We are passionate about the prioritization of robust funding for the NIH and the NCI regardless of the economic climate, and we're firm believers in a strong FDA as well as iron-clad patent protections for both inventors of compounds and the pharmaceutical and biotech industries. Our Scientific Advisory Council chairman, G. Robert Pettit, Ph.D., is the former director of the ASU Cancer Research Institute and in our view one of the most prolific, if not the most prolific, drug discoverers on the planet. ICAN is also a member of the *National Coalition for Cancer Research/ NCCR*, the *Coalition for the Advancement of Medical Research*, the *Alliance for a Stronger FDA*, and the *Personalized Medicine Coalition* to name a few of our favorite umbrella organizations. ICAN is blessed with the incredible talents of one of the best healthcare lobbyists in the business, Linda Jenckes in Washington, D.C. Last year, ICAN nominated one of our favorite and most impassioned cancer survivors and advocates to be part of the FDA's drug approval framework, and we were delighted when that patient was accepted and trained; he will soon be heading to his first ODAC (Oncologic Drugs Advisory Committee) meeting, and he has been blogging on the ICAN website about the publicly-disclosable aspects of this exciting new experience.

At the Arizona state level, we spearheaded efforts which led to special protections for the inventor group of anticancer compounds, in addition to which, we led the effort to get passed an Anticancer Drug Discovery and Development Program that benefited cancer researchers to the tune of $10 million. We've worked hard at the grassroots level, and in testimony before state legislatures, on the issue of parity for oral chemotherapy. We are also involved in major research initiatives and the development of Remission Coach[SM] our medical information search system and the customized advocacy programs that are subsumed under that enterprise.

How does ICAN get involved in epigenetics research?

We get involved as voracious consumers of epigenetics literature and as correspondents with epigeneticists and other scientists. We are the grateful consumers of the published work product of your superstar line-up at the upcoming World Epigenetics Summit. In addition, we are

involved in the field through the epigeneticists we are planning to bring aboard our various councils. We have researchers of a plethora of peer-reviewed journals spanning seven time zones—all volunteers—who are delving into epigenetics literature along with our staff which is keeping us abreast of the latest developments. This is why the World Epigenetics Summit is so crucial to ICAN as a report card on where the field is. We follow the Dream Team in Epigenetics via Stand Up To Cancer (SU2C). And fortunately for us all, the wonderfully articulate leading lights at Johns Hopkins/ Kimmel in Stephen Baylin, M.D., and at USC/Norris in Peter Jones, D.Sc., Ph.D., have a lot of company now, as epigenetics has become a worldwide translational research effort and passion spanning many fine institutions.

"Epigenetics issues have become a staple of our more than 80 named programs at ICAN."

We are in the process of assembling our own dream team at ICAN. Following an extensive international search, we brought on Scott M. Kahn, Ph.D., Director of Basic Urologic Research, at the Saint Luke's-Roosevelt Health Science Center and Assistant Professor of Clinical Urology, Department of Urology at the Herbert Irving Comprehensive Cancer Center/ Columbia University, as chairman of our newly-formed Biomarkers Council. Scott is an accomplished oncology research scientist and early on was an outspoken advocate for personalized approaches to cancer care. He will represent ICAN on the last panel of the World Epigenetics Summit, and we're thrilled about that. Scott brings a deep passion to improving human cancer treatment and is a compelling spokesman for translating the promise of biomarkers and epigenetics to the world of cancer patients. Two other leading scientists who have joined ICAN are Brett R. Johnson, Ph.D., who has defined novel oncology drug development targets in academia and industry and is ICAN's representative to the *Alliance for Safe Biologic Medicines*, and Ajay Malik, Ph.D. a Genentech-trained cancer biologist who has an interest in predictive and prognostic biomarkers. Ajay helps moderate our ICAN Linkedin group and will be working with our *Carliser Rodriquez Gynecologic Oncology Biomarkers Program*. One of our top strategic advisors, Nathan Nagel, CEO of Oncology Pharma Ltd in the UK, has introduced us to leading epigeneticists and scientists from other disciplines. Nathan seems to know everyone involved in cancer research or treatment.

Epigenetics issues have become a staple of our more than 80 named programs at ICAN. As an example, one of our top programs at ICAN, the *Brenda Diener Lung Cancer Biomarkers Program*, named in memory of a beloved patient, is concentrating on lung cancer biomarkers and lung cancer epigenetic biomarkers. We are recruiting nationally and internationally for scientists and oncologists in the biomarkers and epigenetics arena to serve as volunteer members of our various councils or as "senior editors" focusing on some of the issues in our named programs, to help take ICAN to the next level of accomplishment for the benefit of our patients. Summit attendees may contact Scott or Brett/Ajay at ICAN via **biomarkers@askican.org** or **epigenetics@askican.org**. We expect our Biomarkers and

"One of our internal strengths at ICAN is our ability to translate tough and otherwise mind-numbing concepts into language that patients and their families can understand."

"A major goal of our Board Chairman Sherry Weinstein is to have an Epigenetics Advocacy Center and a Biomarkers Advocacy Center."

Epigenetics councils to be leading advocates in the field globally and to translate for patients the important advances the field is making.

In the coming months, we will have volunteers and ICAN Summer Interns assigned by Dr. Kahn, via our HR and Communications Directors, Esraa Halim and Caryl St. Claire, working with ICAN's Director of our Research Team Leaders, Regina Marie Klopfer, and Senior Citations Editor Lee Bentov, PhD, RN. These volunteers will be poring over the first-rate World Epigenetics Summit brochure and Program materials both pre- and post-event methodically to search out all the peer-reviewed literature on a per-speaker or per-compound or per-methodology/per-technology basis to add to what we have in-house. We could keep 200 more interns occupied just in the biomarkers/epigenetics area alone.

One of our internal strengths at ICAN is our ability to translate tough and otherwise mind-numbing concepts into language that patients and their families can understand so that they can actively participate with their medical teams and make the most informed decisions. We have a special writing team at ICAN to translate abstruse concepts into patient-friendly language: our Chairman of the Board of Trustees, the indefatigable and brilliant Sherry Weinstein who has done so much to build our organization; the multi-talented Chairman of our Physicians Advisory Council Robert H. Tamis, M.D.; and our highly creative Webmaster, strategic thinker, and special advisor Mike Seifried. What we'll be producing in terms of brochure copy and web presentations on epigenetics will have to clear those three high editorial hurdles first—all to the patient's benefit. We have a design team in Rupert Reyneke in California and Megan Godbey in Virginia who are able to render complex epigenetic concepts into pictorials as well as diagrams that are fun, staff-friendly, and patient-accessible.

What is the biggest hurdle you face in keeping up with the field of epigenetics?

Funding. We are perpetually looking for major sponsors or for donations in any amount to underwrite all of our programs and projects and to robustly to fund ICAN's Personalized Medicine and Cancer Case Management Programs so that we can take on more cases and not have to put patients on waiting lists because of lack of staff and resources. PwC estimates that the personalized medicine industry right now is $24 billion in sales in terms of diagnostics and targeted therapeutics and will probably reach over $40 billion in sales by the year 2015. That's why attending the upcoming Summit and following the progress of all the -omicists and the epigeneticists will be central in understanding how to deal with this ever-accelerating and complex field of personalized medicine.

We run such a tight ship here that we make sure our board governance, which includes hundreds of pages of board policies, is second to none. Keeping ICAN's overhead remarkably low, we take pride in the fact that more than 94% of every donation supports our Patient Program Services.

A major goal of our Board Chairman Sherry Weinstein is to have an

"We take the view that the global oncology and neurology communities need to get patients into clinical trials earlier in their course of treatment..."

Epigenetics Advocacy Center and a Biomarkers Advocacy Center (each to be named for a generous donor) at ICAN. We are, therefore, on the lookout for those individual philanthropists, family foundations, or pharma and biotech companies that could provide such significant funding.

Lack of consistent access to all the information we need in the epigenetics area is another significant obstacle for us. Internally, we are trying to devise spreadsheets on top of spreadsheets to track who is doing what. Any readers of this interview or any Summit attendees could help us out by taking the $5000 and $9000 proprietary reports and tomes in the area that they procure throughout the year and sharing those with us via purchasing a second subscription for ICAN. We obviously do not have the budget for even one-tenth of the price of those reports, and it would support our mutual goals tremendously if we were to have access to them. So if your readers could send us anything that they think could help us learn more about the area—their full articles in peer-reviewed journals, new textbooks, etc., it would be such a great boost for us. Or when they spend $1000 a year to resubscribe to something, please order an extra subscription for ICAN.

And a special note to seminar and symposia leaders: there are always "no-shows" via unexpected illnesses or people who simply can't attend at the last minute. That's an important part of our wish list: for some of our scientists (on all coasts here and abroad), to be "comped" to your important conferences. Again, the ultimate use in educating ICAN personnel to the most detailed extent possible is that it's the patient who needs to be armed with the right questions for their oncology teams. And we're the ones in the global cancer community talking to those patients, one by one, question by question, and helping oncologists as well as patients and their families explain what the reality and promise of epigenetics means in particular and personalized medicine in general to their treatment plans going forward. We're at the frontlines, and we need more ammo in the form of full articles, treatises, conference reports, and reviews of the field to help YOU, the esteemed epigeneticist or molecular biologist, translate the important work you've accomplished for late-stage cancer patients.

What compounds interest you as the most promising in the epigenetics field?

We try to keep up with the mounting literature on Heat Shock Protein 90 and what is happening with the progress of HSP90 inhibitors such as 17AAG and IPI-504 in Phase I and II clinical trials. The prospect of targeting HSP90 with drugs to upset the applecart of malevolent oncogenic client proteins that affect so many solid tumors and blood cancers, in terms of cell growth, is a cancer advocate's and a metastatic cancer patient's dream. A drug like PU-H71 might hold great promise for triple-negative breast cancer patients, as it appears to derail, degrade, or deplete a dozen different proteins. HSP90 inhibitors could also help HER2/Neu over-expressors. We are going to see the development of new biomarkers to track all this, and that will open a new chapter for patients who are dealing with some of the

most lethal tumors. ICAN takes the view that the global oncology and neurology communities need to get patients into clinical trials earlier in their course of treatment especially when there are promising mechanisms of action involved.

There could be huge benefits from HSP90 inhibitors for lung cancer patients down the road since mutant EGFR is an HSP90 client. It's hard to think of a solid tumor that won't be impacted by HSP90 inhibition, and we'd love to see the HSP90 inhibitors that make it through the approval process so that they can be added to gold standard blood cancer combo cocktails as well. A chief focus of our *Tom Tyne Cancer Research Program* is keeping SCCHN patients informed about HSP90 inhibition. We're evaluating right now whether a chemo-naive NSCLC patient should enter an HSP90 inhibitor clinical trial that is being paired with a proven cytotoxic, since she may fit right into the sub-population that has achieved the highest response. We're also hopeful about the prospects of BIIB021 for GIST patients. Across a range of solid tumors and blood cancers, it will be surprising if an HSP90 inhibitor is not included in first-line regimens as a matter of course.

The promise of HDAC inhibition fascinates us. Chang Qian, Bernd Nentsch, and Sheraz Gul's presentations at the Summit will be most instructive. We want to understand everything we can about CUDC-101, Curis' EGFR/HER2 and HDAC inhibitor now in Phase I/1b trials. Plus the importance of resminostat in KRAS-mutant tumors as a component part of FOLFIRI down the road in the colorectal setting. We look forward to Dr. Gul's analysis of romidepsin, the natural product which targets HDAC enzymes. Since we want to understand the side-effects of HDAC compounds, Simon Jones' presentation about next-generation HDAC inhibitors might be the most pivotal to us in terms of our advocacy services in this area.

We are looking forward to WES speakers sharing their unique and compelling insights at the upcoming Summit so that we can highlight the essence of those presentations in our ongoing Patient Services.

"The prospect of targeting HSP90 with drugs to upset the applecart of malevolent oncogenic client proteins...is a cancer advocate's and a metastatic cancer patient's dream."

ICAN leadership will be sharing their experiences in cancer patient advocacy at the World Epigenetics Summit conference taking place in Boston, MA, 26th - 28th July 2011.