

# Your Good Health is a Workforce Issue

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## ABSTRACT

The high performance computing (HPC), cyberinfrastructure, and research and academic information technology communities are small - too small to fulfill current needs for such professionals in the US. Members of this community are also often under a lot of stress, and with that can come health problems. The senior author was diagnosed with Stage IV cancer in early 2017. In this paper, we share what we have learned about health management in general and dealing with cancer in particular, focusing on lessons that are portable to other members of the HPC, cyberinfrastructure, and research and academic information technology communities. We also make recommendations to the National Science Foundation regarding changes the NSF could make to reduce some of the stress this community feels on a day-in, day-out basis.

The key point of this report is to provide information to members of the cyberinfrastructure community that they might not already have - and might not receive from their primary care physicians - that will help them live longer and healthier lives. While our own experiences are based on one of the author's diagnosis of cancer, the information presented here should be of general value to all in terms of strategies for reducing and detecting long-term health risks. Our hope is that this information will help you be as healthy as possible until you reach retirement age and then healthy during a well-deserved and long period of retirement!

## CCS CONCEPTS

• **Social and professional topics** → **Computing profession**;

## KEYWORDS

health, preventive testing, stress, SAD, Standard American Diet, workforce development, work/life balance, cancer

## ACM Reference Format:

Craig A. Stewart and Marion Krefeldt. 2018. Your Good Health is a Workforce Issue. In *PEARC '18: Practice and Experience in Advanced Research Computing, July 22–26, 2018, Pittsburgh, PA, USA*. ACM, New York, NY, USA, Article 4, 8 pages. <https://doi.org/10.1145/3219104.3219107>

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*PEARC '18, July 22–26, 2018, Pittsburgh, PA, USA*  
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ACM ISBN 978-1-4503-6446-1/18/07.  
<https://doi.org/10.1145/3219104.3219107>

## 1 INTRODUCTION

The senior author (Stewart) was chair of the 2012 XSEDE conference. Most conferences begin with some sort of welcome from the chairperson. In 2012, those opening remarks included the announcement of the death of a key person in the cyberinfrastructure and computer science community - the second year in a row such an announcement started the conference. The 2012 XSEDE conference began with an announcement that Allan Snaveley had just died of a heart attack the prior weekend. The prior year, at the start of the 2011 TeraGrid conference, attendees had been shocked to learn of the death of Phil Andrews, also of a heart attack, also just before the conference began. (2011 was the last TeraGrid conference. Like TeraGrid itself, the TeraGrid conference was succeeded by the XSEDE conference, which has now of course been succeeded by PEARC). Over the years, two valued colleagues died of colorectal cancer - David Moffet of Purdue University and Keith Jackson of the Lawrence Berkeley National Laboratory. These deaths were tragic from a personal perspective. From the perspective of our professional community, these deaths represented a loss of decades of leadership and service from these four individuals - decades of service from which we would have all benefited had these experts lived out their lives in keeping with the expectations described in standard actuarial tables. Far too often we in the cyberinfrastructure community put too much emphasis on the stressful tasks right in front of us, and not enough attention on our own health. It is one thing to work hard. It is another thing to work ourselves to the point that it is unhealthy<sup>1</sup>.

And why are we - the authors - right now concerned about health care? To the shock and dismay of senior author Stewart and co-author Krefeldt (Stewart's wife), Stewart was diagnosed with colorectal cancer on 13 February 2017. This happened during what was expected to be a routine colonoscopy. On 14 February came the news that the cancer was already advanced to Stage IVa. (Yes, this was the worst Valentine's Day ever).

Stewart getting colorectal cancer was a low probability event. Yet as colleague John Towns put it, "low probability events are low probability events because they do happen from time to time; otherwise they would be no probability events" (personal communication). Any one particular type of cancer is in and of itself rare, but roughly 40% of us will develop cancer at some point in our lives [1]. Summed across all different types of cancer, cancer is very common and is becoming more common all the time. And cancer is just one of the many health risks that stalk all of us. With our minds recently focused on health, our goals in this paper are to:

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- (1) Reduce the stigma associated with talking about cancer by openly discussing what we experienced. This stigma is still very strong, and not discussing this important health risk openly can cost lives.
- (2) Provide a sense of what it was like for us to live through a year and more after of life post-diagnosis. Our intent is partly to reduce the sense of stigma regarding cancer, and partly to present some rational data regarding cost/benefit choices we all make regarding work vs. preventive medical care.
- (3) Relate lessons about health management that are usable to all of us working in the cyberinfrastructure (CI), high performance computing (HPC), and research information technology (IT) fields. These suggestions are made knowing that we in these communities have chosen careers that are inherently more stressful than many jobs in private sector information technology. We have made these choices because we believe in the inherent value of what we do, but we shouldn't be blind to the long-term health consequences of stressful job situations.
- (4) Offer advice to the National Science Foundation (NSF) regarding steps that it could take that could reduce stress levels among the portion of the national STEM (Science, Technology, Engineering, and Mathematics) community that derives funding for part or all of their salaries from NSF grant awards.

In addressing the goals above, it is our hope to nudge [20] you, the reader, to make good choices about your own health management. Our own experiences are with cancer, and there is thus some particular emphasis on that experience in this report. However, the general suggestions we make regarding reduction of long-term health risks and early detection of health problems should be applicable to all readers.

## 2 THE CAREGIVER'S VIEW AND THE PATIENT'S VIEW

In any given situation there are multiple viewpoints. In this section we present the viewpoints of the senior author and patient (Stewart) as well as those of the patient's wife and caretaker (Krefeldt). Our writing styles are different, and we have tried to be clear about whose viewpoint is being presented at any given point in this report.

### 2.1 The soon-to-be patient's view - Craig

I have always been considered to be pretty healthy. I exercise a lot. I've never been a smoker. I have typically maintained a healthy BMI (Body Mass Index). I never drank in excess (rarely beyond the minimal levels I was driven to by some faculty colleagues). I come from a family with no recorded history of cancer save two cases involving heavy users of tobacco products. When one considers the standard lists of risk factors for colorectal cancer, I rate very low on the main criteria. On top of that, I was thoroughly checked over in 2011 when I was being considered as a kidney donor for a family member. I was screened head to toe - including a CT scan for cancer which showed that at that point I was free of cancer.

In perhaps late 2015 I realized that my running workouts just weren't of the quality I expected. There was nothing specific I could

point to. But workouts just didn't feel right, and neither did races. People that I should have been able to beat easily were beating me. Sometime in 2016 I noticed that I was going to the bathroom more often than I was used to. When I thought about this at all, which was rare, I wrote it off to stress. 2016 was indeed a really stressful time. Then sometime after New Year's of 2017, my wife Marion said "we need to talk." My wonderful wife went on to say, "You go to the bathroom too many times a day. You need to see a doctor." I saw my personal care physician, who thought a colonoscopy was worthwhile but who also agreed that, based on my symptoms, the one thing it probably was not was colon cancer. In particular, I had not lost weight, and my hemoglobin levels were just fine.

I chose to do my colonoscopy without anesthesia because I really dislike anesthetics. As my colonoscopy was started, I could watch the same screen the gastroenterologist was watching. Just a few seconds into the procedure - certainly less than a minute - I saw something on the screen and said, "Boy, that doesn't look happy." The doctor's reply was, "No, that's cancer."

### 2.2 The caregiver's view - Marion

It is hard to understand how serious health issues can be unless you have experienced them yourself. But to give a sense of what the consequences of illness are, let me pick up the story from this side of this experience as of the 13th of February 2017.

February 13 of 2017 was the most horrible day in all the years Craig and I have shared.

I remember sitting in the waiting room. The TV was playing some sort of soap opera, I think. The hours felt like days. I read something on my Kindle. I have no idea what.

A staff member fetches me to bring me back to Craig's room. She does not look at me after calling my name; she just looks at the floor.

I sensed a shadow. Please, oh please, just let it be something simple.

Instead, the first words out of Craig's mouth were, "I have cancer. I have colorectal cancer. I am so sorry."

I remember going numb, just numb, before feeling this deep sense of despair. I inhale to the lowest part of my body, but I cannot exhale. Probably never again.

Nevertheless, the despair gives way to fear. Pure fear. The kind that makes your legs buckle while you are trying not to throw up.

After further testing, and meeting with an oncologist in Bloomington the next day, Valentine's Day, I hear numbers: Stage IV, 20%, 5%, 5 years. (20% chance of Craig being alive after 5 years; 5% chance of being alive and disease free).

I am sure other things were discussed, but I have no real recollection of the conversation, just the numbers. I left there thinking: I hate this place. I HATE this place. It smells in here. The lights are buzzing. The carpet is dingy. I'm not sure if any of this was actually the case. But better to focus on that than the message. At least for the moment.

I feel hot and cold. I cannot sleep. Cancer. Craig. I will be alone.

I have no idea how to make that work. Never mind about me. What about our children? While they are adults, they dearly love their Dad, teenage years notwithstanding. Then there are the grandkids, who adore their Opa.

I think of all the crazy hours Craig and I have worked, but in the last few years, particularly Craig.

From my perspective, his health deteriorated slowly, much like the fable of the frog in the boiling pot.

I rewind our conversations concerning his work schedule and his health. High blood pressure, high blood sugar, digestive issues. I would mention the symptoms and the increase in severity frequently. Our conversations followed a pattern, they were predictable.

There is a grant proposal I must write, a paper I must edit. A talk I must prepare, a conference I must attend. A personnel issue I must solve. I knew at some point, someone, something would lower the boom.

Well, cancer does that, and quite immediately and effectively.

Somewhere along the line, my fear turned to fight.

Fight with a thick layer of cortisol and adrenaline. The kind that makes your head buzz and your tongue feel thick and makes you itch all over.

Nothing makes it stop. Not sleep, not wine, not showering, nothing.

Call someone, I said: DO SOMETHING. Don't just stand there. We are going to Indianapolis, or MD Anderson, or Dana-Faber, SOMEPLACE.

How DO we tell our kids? We procrastinate, that's how. We tell ourselves that we need to digest this information before we can talk about it. Then we procrastinate some more.

I tell our daughter. She just sits down on the floor in her kitchen and weeps. Craig tells our son. He is completely distraught as well.

Why Craig, they ask. Why not some rapist, murderer, or terrorist? Cancer does not discriminate. It does not care if you contribute to society or take away from it. Cancer is very unscrupulous and smart, very, smart. Smarter than any of us, we say.

Running buddies. I have running buddies. The 17th of February is a Friday. We run on Friday mornings. The car pulls up to the house to fetch me on the way to the trail. Pull around the corner, I say. I do not want Craig to see me fall apart. I share the news, share the numbers.

Were we all silent on the drive to the trail?

I just remember the numbers, and that the odds are Craig is going to leave me.

Running is good for the soul. Running with friends is good for everything. Our little group of 3 or 4 run ladies has run through a divorce, death of several parents, and a case of multiple myeloma. We add colorectal cancer to the list.

Anyway, by now Craig and I have a plan.

We are going to the IU Simon Cancer Center. I don't know if it will be better or worse, but it will at least be different. Maybe there the lights will not buzz, the carpet will not be dingy, and the numbers will be better. On the other hand, maybe we will get there and they will tell us to go on a nice long vacation.

Craig drives. I cannot. Actually, I remember thinking: I cannot do this. I cannot do any of this. However, about halfway to the Simon Cancer Center it occurs to me that I really do not have a choice in the matter.

I remember seeing this card in a Starbucks, the caption of which was, "Yeah, life sucks sometimes. So put your big girl panties on

and either fake it or make it baby cause ain't nobody got time for that."

I decide, yes, I can fake this.

On the drive into Indianapolis, I make it a point to enjoy the view of the river. For the first time in days, I notice that the sun is shining. Maybe it has for days. I have no clue.

The oncologist says: I am glad you came in here while we still have something to work with. At that very moment, I moved from faking it to making it. I will become the best caretaker that I can be.

I felt like I was just promoted to a new job with high stakes, for which I am not the least bit qualified.

Since being promoted has happened in my professional life, with a good measure of success, I have confidence. I got this, you damn cancer you!

With the help of a clinical psychologist, a psychiatrist, our children, my family and friends here and abroad, I started to re-enter my life.

Slowly, tenuously, but forever looking over my shoulder. Always anticipating bad news or complications.

In retrospect, I think I also became somewhat agoraphobic. I only left the house when I needed to. I only read my email every few days, not knowing how to or not having the energy to answer all the well-wishers. This was probably not the best approach, but most people stuck with me.

The first complication came just before our anniversary. As a side-effect of Craig's chemotherapy, the tumor tissue became so inflamed that it caused a complete blockage of Craig's colon. We needed to make it from Bloomington to Indianapolis, as soon as possible. It was 4:30 in the afternoon. Indiana State Highway 37, which connects Bloomington and Indianapolis, was bumper to bumper during miles of construction. I got us there within 55 minutes, driving through and around orange cones and sometimes in the median. I thought if the police stop me, good for us, they will give us an escort. I don't think I have ever driven this recklessly in my entire life. On our wedding anniversary, April 21, Craig had a colonoscopy in which a stent was placed in his colon to hold it open. (Worst anniversary ever.) The same side-effect happened after the radiation treatment, but we knew more and the event was much less dramatic.

Somewhere in the summer, we received the good news that, since the tumors had shrunk a lot Craig's surgery would be in July rather than in October.

Where to stay for eight days? Craig's surgery was the Friday before the NASCAR Brickyard 400 race in Indianapolis. Almost all hotel rooms are booked. Some nondescript hotel by the airport, that's where we stayed.

Our daughter joins me. So does my mother-in-law. Our son had scheduled a family vacation. Go, just go. Cancer cannot take everything away from us, we say.

The night before the surgery we are in the hotel room. Craig falls in the bathtub. I go back from making it to faking it. Not very well either.

The surgery is long, eight hours instead of three, it turns out. The estimate that Craig had for 3 hours was just for the liver surgery, not the whole procedure. But at the end the surgeons are optimistic.

On day 2 after surgery we walk, and we have walked most days since. There were 8 weeks of chemo sessions left after surgery.

Craig rang the bell in the infusion center - signifying the end of his chemotherapy treatment - on the 11th of October. The preceding 9 months had been awful, just awful.

It is so hard to watch a person you love be afraid and suffer so much physical pain. I probably remember the pain moments better than Craig. Pain and painkillers both produce a pleasant brain fog.

The next surgery was November 30. The purpose of this surgery was to reverse the ileostomy that Craig had been given during his cancer surgery in July. In comparison to everything else, the ileostomy reversal seemed relatively minor. We had to stay close to the IU Cancer Center in case there were complications. This time there was no hotel room available either because of some convention, but our social worker connected us with Fairhaven - an organization that provides apartments close to campus for cancer patients. They provided us a nice small apartment, just a short walk from the hospital. We celebrated my 60th birthday there. In 2017, there was not a single celebration or holiday, other than Thanksgiving, that was not impacted somehow by cancer.

2017 was also the first year in 35 years that we were in Indiana all year. I was not able to visit my parents, who live in Germany and are in their 90s. And my dad can't hear, so phoning is a challenge.

I also did not take care of myself as well as I should have throughout this process.

I have not had a physical, a mammogram, or a colonoscopy. How crazy is that?

This only occurred to me as I was going through our medical receipts, of which there are many.

I have always heard that being a caretaker is harder than being sick. I do not know about that. But it sure is not a cake walk. The sacrifices do not become clear until the immediate crises are over. We are currently in that territory. It has become clear to me that no one can be this sick by themselves. And no caretaker can be well throughout this process without professional help. There is no shame in that.

I have had to rely more on my family and friends for support than I ever thought possible. That does not always feel comfortable. It is counter to my nature. I think what saved my sanity were just a few simple things (in order): my love for Craig; anti-anxiety medication; our kids, who were omnipresent, on the phone and in person at the infusion center; a brother I knew I could call at 2am, any day (I did that a lot, always in tears and desperate for answers, of which there were none); exercise, mostly with my running buddies (without them, there would have been times when my head would simply have exploded); my Kindle and mindless reading of simple novels that took me to places I now cannot even remember.

Moreover, I believe I have identified important issues I must continue to work on: I am a realist more than an optimist. A little bit of optimism really goes a long way. It is o.k. to de-select people who are not helpful, or worse, are a drain on the system. I must remember how fortunate we really are in this unfortunate situation. We have a lovely family, great friends, great medical care, good insurance, the time and opportunity to heal without having to worry about keeping a roof over our heads. I have a friend who has had cancer twice. She says cancer families live their lives 90 days at a time for the first 2 years, then we get 180 days for the next 3 years. She is correct. The language has already crept into our daily conversation, without much fanfare. IF the next check-up is o.k.,

we will register for a half marathon. If the tumor count stays below 3.0, if the THIS. . . then the THAT. If not, go back to the beginning, or some version thereof.

I am really not good at any of this.

I must do my best to enjoy the here-and-now for what it is, and keep my fear of what may be lurking in the next moment from stealing time away from us. This sounded like a platitude at one time. Now it is my mantra.

Am I a good caretaker? I don't know. Probably no better or worse than anyone else in my situation.

A brochure at the cancer center said I would embark on a rewarding journey. Seriously? Who writes these things, anyway? A rewarding journey for me involves a beach vacation or a trip to Italy.

Caretaking is life-disrupting, frustrating, painful, and heart-wrenching. It is time-consuming, exhausting, frightening, and depressing.

I have learned a lot about how medical institutions are run, what you need to say to get your insurance company to actually pay for the coverage you bought, and the many - many - loopholes and exceptions in medical insurance coverage.

I have filled out dozens of forms, signed documents without knowing what they say, and on more than one occasion wanted to storm into the hospital kitchen with a plate of food they delivered that was filled with foods that Craig cannot eat.

But would I ever trade my responsibilities? Certainly not.

Every day I get up and my silent promise is that I will put one foot in front of another and continue to share this journey with Craig.

Would I do anything different today?

Sure I would.

I would not have acquiesced during our conversations about Craig's health.

I would have taken better care of myself during the last several months.

I would answer all the calls and e-mails to let the senders know how much they matter. On many days they were all that got me dressed.

I would take time to paint and garden.

But this is where we are today.

This is not the real ending. It is just the place where I stop telling our story as it has unfolded until today.

### 2.3 The patient's view after the fact - Craig

When I was first diagnosed, I did not fear dying *per se*. What I felt was guilt at having been stupid enough to have not done something to somehow have caught this at an earlier stage, guilt about the possibility that I would die without keeping promises I had made to my wife of more than 30 years, guilt about the pain I was causing her. I trust Marion's account of what happened during 2017 more than I trust my own. Pain is itself a great anesthetic, and other anesthetics were involved at several points of the year. For those who want a running summary of what this time was like for me, I maintained a blog which is available at [17]. As of now, my blog is inactive and it will stay that way as long as I remain in my current seemingly healthy condition. Anyone who reads my blog and Marion's account of 2017 will wonder if we are describing the

same set of events. We are. My description is through the lenses of pollyanna-ish-ness, faith in my wife and my medical team, and a determination that I was going to act as if it was all going to be okay in the hope of a self-fulfilling prophecy. In other words, complete self-delusion.

As I look back on the time leading up to my diagnosis, I have come to the following “after action report” summary of how I got to the point of Stage IVa cancer before being diagnosed:

- Blaming myself. I had noticed that my running workouts and my satisfaction with them had deteriorated in quality. In retrospect this decline was probably noticeable for two years before I was diagnosed. Rather than thinking that somehow this was my body’s fault, I blamed myself. I blamed myself for somehow not working out enough, not working out carefully enough, weighing too much, not concentrating well enough, not being tough enough, something, anything. I did everything but consider the possibility that there was something wrong with my body that was causing it to underperform, and that this was at the root of the problem.
- Health professionals didn’t do everything they might have. Between 2011, when I was checked over head to toe and declared fully healthy, and 2017 when I was diagnosed with Stage IV cancer, I was seen by more than half a dozen different primary care physicians. Not one of them recommended one of the noninvasive tests that might well have detected my colorectal cancer months or years earlier than it was actually found. In fact, while I was being very careful about the known risk factors I faced based on my family history, I did not actually know what tests were recommended for people my age. On the side of things I should have done differently: I let myself fall into a relationship with my primary care physician (PCP) that didn’t work for me. Not that my PCP is a bad doctor; far from it. But the way my PCP’s practice and staff communicated with me just didn’t work for me. I needed a PCP who would have someone call me and say “get yourself into the office by the end of next month for the following tests, period” and I didn’t have that.
- I was embarrassed about talking about bodily functions. By sometime in 2016, I knew that I was going to the bathroom a lot, but I was sure it was somehow my fault. I was too embarrassed about it to ask my wife or a doctor, “Hey, does this seem right to you?”. I was convinced I was not eating carefully enough, or not exercising enough, or something. The instincts that have always helped me in my life and my career kicked in: put my shoulder to the wheel, work harder, try to somehow figure out how working harder would make the problem go away. Of course, this didn’t work, and my high pain tolerance - always an asset in running and work - was counterproductive in this situation. My pain tolerance led me to shrug off things that I should not have shrugged off.
- I am colorblind. In fact, I am almost comically colorblind. Men who are red/green colorblind tend to self-diagnose colorectal cancer later than those who see color properly [13].

I have often said that our greatest strengths are also our greatest weaknesses. One of my greatest strengths has always been the

ability to push through difficult mental and physical challenges without flinching. This time, I should have flinched. Or at least listened to my wife more carefully than I did. I did not.

## 2.4 The caregiver’s view: general lessons after the fact

Now with the benefit of some hindsight, here are some general lessons I have extracted from my experience:

- In anything other than the most mundane and routine Stage I or II cancers, never base one’s reaction to a cancer diagnosis and treatment plan on the basis of the opinions of a general oncologist in a small town or a small city. For any complicated cancer, we recommend going to a person who specializes in the particular cancer a patient has and who practices within a cancer center in a large metropolitan area. And best is to be treated in a large teaching and research hospital and/or cancer center.
- Don’t look at the bills, and don’t read anything on the web. Paid by insurance, out-of-pocket, out on appeal, yet to come. Get the patient healthy first, worry about the bills later. And information on the web? For any given situation or symptom, one can find seemingly authoritative websites with opinions ranging from “this is nothing to worry about” to “you are going to die soon.” But DO read thoughtful and well-regarded books relevant to your situation.
- Don’t feel guilty about the opportunities we have vs. the fry-cook at your local fast food restaurant. The system is designed to be unfair and, it is. Cancer does not discriminate. Health care in the US does. But instead of feeling guilty, we should all work to improve the system. Life, liberty, and pursuit of happiness are supposed to be basic human rights. The health care system in the US does not currently protect those rights uniformly for US citizens. But turn your attention if you wish to the fairness of the US health care system once you have been freed of the day-in, day-out stress of dealing with cancer (or other serious illnesses).
- I would seek professional help before I waited for a psychiatrist to tell me very kindly, yet with some authority, that I needed some help.

## 3 DISCUSSION

Below we discuss risks we have in the cyberinfrastructure and research IT communities, and what we can do to pursue our chosen careers without unnecessary risks to our own health, followed by some recommendations to the National Science Foundation.

### 3.1 The risks we have chosen, and some we did not

We all recognize that the cyberinfrastructure workforce is too small and under too much pressure. In exchange for salaries lower than in the private sector we get long hours, job uncertainty, tons of stress, and the knowledge that we are advancing the state of human knowledge, scholarship, and arts. Many of us think this is a good trade-off. If you are reading this report you most likely have already chosen a high-stress career, or are considering one. For the sake of

your family and your professional/academic community, take steps to maintain your good health in spite of the stressful path in front of you.

Stress in fact is a risk factor for all manner of diseases, although there is not yet a strong link established particularly between cancer and stress [4, 9]. Stress is an overarching risk factor that most people working in cyberinfrastructure experience, and it is one that we often do not think about. Chronic stress takes whatever risk factors we might have and makes them worse, and stress also distracts us from dealing with our health.

Another factor about the information technology community generally is that, by default, a lot of sitting is involved in our work. The dangers of sitting without interruption for long periods of time are significant and only now being well understood [6].

Few of us have actively chosen to eat a terrible diet, but there are clear indications that the general US food industry trend to put more sugar in more foods is dangerous to our health in many ways. This has been exacerbated by worries about the link between ingestion of meats and fats and high cholesterol levels, driving many people to consume more carbohydrates and fewer meats. In fact, carrying some extra weight and the basic “carb-driven” metabolic pattern that we almost all universally enjoy on the Standard American Diet (SAD) creates many health risks [15].

### 3.2 What should we do?

We in the cyberinfrastructure, HPC, and academic IT fields are in a high-risk group for all manner of health issues because of the stressfulness of our jobs. There is only one real option for us if we value our own contributions to the workforce of which we are a part: pay attention to our own health. We recommend the following, based on what we have learned in the past several months:

- Assume that you are the only one in charge of managing your health care. Manage and track your own health records and take responsibility for getting all of the tests recommended for you given your age and other characteristics. No one else is going to track these things for you.
- Perform self-exams regularly. Everyone should do monthly self-checks for skin cancer, breast cancer, and/or testicular cancer. Information on these exams is available at [3, 16, 19].
- Demand that your body works for you. If you are not content with the way you feel, ask a doctor. If your doctor brushes you off, demand good attention to your issues or fire your doctor and get a new one.
- Because we are in a high-stress field (and thus at higher than normal risk of medical problems of many sorts), we should all have annual checkups and get tested for everything that the US Preventive Services Task Force has recommended for preventive examinations [22].

The tests recommended by the US Preventive Services Task Force change constantly, as new medical research and new analyses help medical researchers try to balance costs and benefits of testing. There is an online web form at <https://healthfinder.gov/myhealthfinder/> [7] that will tell you what tests you should have based on your age and gender. But don't count on your personal care physician to recommend to you tests recommended by the Task Force. Some

doctors won't even tell you or ask you about some of these tests. For example, there are a variety of opinions regarding noninvasive tests for colorectal cancer, all of which involve some sort of testing of a person's feces. One of these is called the Fecal Occult Test - a test to see if there is blood in your stools, not to see if your stools have a tendency toward devil worship. No doctor ever discussed any of the now several noninvasive stool tests with either author of this paper, despite clear published guidelines about how helpful such tests can be [14]. Had Stewart either known to insist on one of these tests, or had a doctor suggested one at some point, Stewart's cancer might conceivably have been found at Stage II or III when treatment would have been much simpler. These sorts of tests do tend to have a high false positive rate. Would we take the anxiety of a false positive for having cancer detected when treatment would have been simple? In a heartbeat.

Other things you can do range from straightforward to fairly challenging. They include:

- Avoid sitting for prolonged periods of time. Tips on periodic exercise to mitigate the impact of sitting for prolonged periods are available at [6].
- Take one day a year and give your body and health an annual performance review. If your health is not meeting your own performance criteria, get to your current doctor or get a new doctor who is willing to help you. Take a whole day off, and do nothing but concentrate on evaluating and planning for your own health.
- Consider taking a formal approach to planning for your health and happiness. The bestselling book “Your Best Year Ever” [8] is unusual among self-improvement books in that it incorporates planning for health, happiness, and career as an integrated whole. The workbook “Get Out of Your Mind and Into Your Life” [5] describes an approach to stressful situations called “acceptance and control theory.” This approach can be particularly helpful in understanding how to get control of your own feelings of stress. Consider working with a therapist or mental health professional regarding your mental and emotional health.
- Exercise and maintenance of a healthy body weight. These are, of course, the eternal and iterative goals of us all. The book “Your Best Year Ever” is particularly helpful in that it offers guidance to turn this eternal wish into actionable plans with concrete ways to positively reinforce your progress as you go. If your BMI is outside of the range identified as normal, think about changing that. Correlation, of course, does not imply causation; however, rates of incidence of cancer and rates of obesity in the US are both rising. (And no matter what, obesity is itself a health risk.) There are many suggestions in the literature that leanness confers reduced risk of cancer.
- Consider giving up the Standard American Diet. It is often referred to as SAD for a reason. There is a growing body of literature that suggests that a meat-averse, high-carb diet is unhealthy and out of sync with the evolutionary history of our species. Good references on low-carb diets include books such as that by Sisson and Kearns [15]. Some experts criticize extremely low-carb diets, but you can greatly reduce

your sugar consumption, increase your health, and avoid the pitfalls identified with extreme low-carb diets. In any event, read labels. Manufacturers of food and food-like substances are required to put nutritional labels on packages of food. Those are typically shown “per serving”. Almost anything looks reasonably healthy if you make the portion sizes unreasonably low. So as you purchase any sort of food, and particularly any sort of snack food, do the math and calculate the nutritional, caloric, and chemical contents of what you might eat. Don’t make dietary decisions on the basis of nutritional values for some artificially small portion size that represents much less than the amount you will actually consume. And even when portion sizes are rational, what’s actually in a particular item of food can be quite a surprise.

- Consider adding some sort of mindfulness practice to your day. Even a few minutes a day of getting away from the stream of thoughts that pummel us every day could be good for managing your stress levels. The many approaches to mindfulness practices include several forms of meditation, Tai Chi, Qi Gong, prayer, etc. A good entry point to approaches to mindfulness is Mindful Magazine [2].
- Consider specific things you could do to reduce your chances of getting cancer. Reference books that provide useful information on how to lower your risk of cancer include [12] and [23].

### 3.3 Return on investment in self-care

Return on Investment (ROI) is important in all aspects of investments of any kind of resource - time and money included. That’s true in terms of investments in cyberinfrastructure [18] and it is true in terms of your time and your money. A quick ROI analysis of preventive care for Stewart is as follows: Had Stewart, every year since starting full-time as a computing professional in 1985, taken two days off per year to focus on health self-evaluation and good, thorough checkups, and paid \$1,000 per year out of pocket on average for tests that were not covered by insurance, and as a result had his colorectal cancer been detected say at Stage III rather than Stage IV, the ROI on lost productive work time would have been greater than 10, and the ROI in terms of medical costs would have been much greater than 1. (Out-of-pocket medical costs have been significant even with a good insurance policy.)

### 3.4 Things the National Science Foundation could do

The National Science Foundation could also recognize and change some of the pressure that exists in their processes, and practice a bit more of what they preach regarding work/life balance [11]. Several years ago, the National Science Board (NSB) recommended that the NSF should “prohibit voluntary committed cost sharing” within grant proposals [10]. The NSB recommended that the “Facilities, Equipment, and Other Resources” document within grant proposals submitted to the NSF be expanded to “contain a comprehensive description of all resources necessary for and available to a project, without reference to cost, date of acquisition, and whether the resources are currently available or would be provided upon receipt of the grant...” The policies enacted by the NSF in regard to these

recommendations created a vehicle for Principal Investigators and proposal teams to make unspecified and unquantified promises understood in detail by no one - not the NSF, not members of NSF-appointed review panels, not the PIs themselves, not their teams of colleagues, and most certainly not the fiscal and human resources authorities of their home institutions. People whose funding depends upon grant awards - or who are responsible for staff whose funding depends upon grant awards - may feel compelled to be as competitive as possible for cyberinfrastructure-related grant funding. This can go to the point of feeling coerced to promise doing too much with too little in order to win a major grant award. There is little or no vehicle for oversight of the contents of the “Facilities, Equipment, and Other Resources” before proposals are submitted. After a grant award has been executed there may be no mechanism for fulfilling promises made in that section of a grant proposal other than taking on unreasonable workloads. This can be a creator of unhealthy stress and overwork. If the NSF were to change its policies and require description in quantitative terms of resources described in the “Facilities, Equipment, and Other Resources” document, the result would be better planning for all. In particular, proposing organizations, including PIs, would have a clear statement of commitments being made. The NSF and NSF-appointed grant proposal review panels would also be presented with a clear statement of the commitments being made in this portion of grant proposals and would have the ability to evaluate such commitments for rationality, appropriateness, and ability of the proposing institution(s) to fulfill the commitments made. This change could simultaneously improve the quality of proposals, the quality of research done with NSF funding support, and reduce stress on researchers generally and members of the cyberinfrastructure community particularly.

Furthermore, the NSF could practice more of what it preaches in terms of “work/life balance” [11] through very simple changes in scheduling of proposal submission deadlines. Scheduling proposal deadlines away from commonly observed holidays would reduce stress on this community (and members of the families of people in this community) significantly.

There is also an issue related to the Office of Management and Budget 2 CFR Part 200.430 [21]. One interpretation of this document holds the following: if a person is 100% funded on one or more grant awards, then that person has no agency to spend her or his own time working on anything related to scientific or engineering research beyond the grant or grants on which they are funded. That is, according to current NSF policy and auditing practice, if a person is 100% funded on one grant or some combination of grants, they may do no work related to preparing other grant proposals - even on weekends - to secure sustainability of their own funding for the future. A clarification that allocations of effort percentage are based on some rational interpretation of a work week - with every individual having the ability to work on their own time on their own research and grant proposals - would recognize and validate the agency that each person working in a field of science or engineering should have. This would reduce the stress felt by the many people working in the science and engineering workforce who are supported exclusively by federal grant funds.

## 4 CONCLUSIONS

We in the cyberinfrastructure, HPC, and scientific and research computing communities are too few, too stressed, and too busy. And it takes years upon years for a person working in these areas to become well versed in the core aspects of our disciplines and the key aspects of the disciplines we support. We owe it to ourselves and those who care about us to live a long healthy life. The very fact that you are reading this paper suggests that you are a cyberinfrastructure expert devoted to aiding research and discovery in science and engineering, or are considering a career as such. We can point to a handful of important leaders in our community who left us far too early, leaving gaps in their own families and circles of friends and depriving the research community of their expertise as well as their pleasant presence.

Your personal care physician is unlikely to understand how important stress is for you as a risk factor in your long-term health, and is unlikely to ask you to take all the tests recommended by the relevant medical experts for a person of your age and gender, and not taking the impact of your stressful career into account. Your two choices are to take control and insist on tests, or to take your chances with what your doctors ask for and order. The latter was the choice taken too often by the senior author of this paper; it did not work out well. While this particular discussion has focused more on cancer than other health risks, because of the authors' experiences, each one of us in the cyberinfrastructure community has a unique genetic makeup and personal health history. As shown by the list of colleagues at the beginning of this paper who died as a result of heart attacks or colorectal cancer, there is ample evidence that we live in a stressed, high-risk profession. Get early screening tests recommended by medical experts, get early screening tests appropriate to your own family history, get early screening tests appropriate for a person in a high-stress, high-risk profession, and protect yourself. Whatever your personal medical risks are, taking good care of yourself and early detection of any serious medical issues are key. If you are behind on the screening tests you ought to have, go get caught up with a good, thorough physical. Be productive, work hard, do good things - but don't neglect your own health in the process.

The cyberinfrastructure workforce is too small as it is, and there are people who care about you as a person. So help our workforce: stay healthy and productive till you decide it's time to retire.

Last and not least, a caveat: the purpose of this paper is to get you thinking about your health and your life, not to dispense medical advice. Get medical advice from a qualified caregiver!

## ACKNOWLEDGMENTS

Most importantly, the first author would like to thank the second author for keeping him alive. We would both like to thank the doctors, nurses, staff, and volunteers of the IU Simon Cancer Center for their excellent and compassionate medical care. We would like to thank the CaringBridge blog site for providing a blogging and communication platform, and the Fair Haven Foundation for providing an apartment for us to use during two parts of Stewart's medical treatment.

We would like to thank Stewart's colleagues at IU, as well as the leaders to whom he reports, for their deep support during the

treatment and recovery processes. Special thanks go to David Y. Hancock, Matt Link, Therese Miller, and Von Welch for picking up significant parts of Stewart's job responsibilities while he was undergoing treatment. We both thank friends and family for their support. This work was supported in part by the Indiana University Pervasive Technology Institute, which was created with major support from the Lilly Endowment, Inc. (which in the context of this work has no ties to the Lilly pharmaceutical company). We thank Winona Snapp-Childs for her editorial expertise and effort. We thank R. Moore, G. Moore, and other anonymous reviewers for review and suggestions of prior versions of this paper. Any opinions expressed here are those of the authors, and do not represent any opinions by any organizations that have employed or supported us. Any errors contained in this report are the responsibility of the senior author, because his wife is always right.

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