

# Researchers told to share data

## Funding at stake if results delayed

BY LENNY BERNSTEIN  
THE WASHINGTON POST

The government unveiled new policies Friday designed to make findings from clinical trials of therapies and devices more widely available, warning that it would block future funding for universities and other institutions that do not comply.

The updated rules are designed to encourage more participation in research studies and to spread the results of those efforts faster and more completely to the patients, physicians and clinical investigators who need them. Officials also described them as an effort to enforce the pact with volunteers in medical experiments that they or others will someday benefit from their participation in research.

"We, as a community, have a disappointing record of making those results available," Francis S. Collins, director of the National Institutes of Health, said in a briefing for reporters. "This is about maintaining the trust that we have with participants in clinical trials who volunteer to take part in these efforts with the expectation that it will add to the body of knowledge."

Some of the changes have been in the works for years. But the effort was hastened by Vice President Biden's threat in June to cut off research funding to medical institutions that don't report the results of their research. Biden wants more information disseminated more quickly to aid research in the Cancer Moonshot that he is leading.

Collins noted that a 2014 review of 400 research studies showed that 30 percent had not reported their results to clinicaltrials.gov, the government repository for such information, four years after completion. "That's clearly unacceptable," Collins said. Under a 2008 rule, federally funded researchers are

supposed to deposit their results within a year of a clinical trial's completion. Another examination of 51 academic medical centers revealed that 43 percent of their clinical trial results were not published two years after completion.

Biden said that fewer than five percent of cancer patients enroll in a clinical trial, often because patients and doctors don't know what trials are available. About 31 percent of the open trials on clinicaltrials.gov are for research related to cancer.

Beginning on Jan. 18, researchers in most studies of therapies and devices funded by NIH or regulated by the Food and Drug Administration will have 90 days to come into compliance with the new rules. For some universities that have been lackadaisical about following existing policies, that may require some effort. The NIH gave out nearly \$24.5 billion in research grants in fiscal year 2015.

The new rules issued by the Department of Health and Human Services expand the kinds of research that must be registered, demand quicker registration and require more information about results, the participants involved and how the research was conducted. The government also wants more information on research that failed to achieve its goals, which, Collins noted, often can be valuable to future studies, and therapies that have not yet been approved by the FDA.

Collins acknowledged that the government cannot ethically halt ongoing clinical trials as an enforcement technique, but he said NIH intends to be vigilant about blocking future grants for institutions that do not comply.

Biden also announced improvements to trials.cancer.gov that will allow researchers to more easily find trials for specific cancers and types of people.

# A shelf that became a shrine

There's a shelf in my custom-made medicine cabinet that still is crammed with my husband Jim's personal hygiene items. I pretty much ignore it, so it's remained the same for 5½ years since shortly after Jim died from pancreatic cancer in December 2010.

Despite usually ignoring it, I've almost thrown the stuff away several times without success. So there it sits, occupying space with no chance of its owner ever using it again.

The medicine cabinet is part of the built-in wooden structure that also has a pullout clothes hamper and a linen closet where I keep towels and other items.

The lower shelves of the medicine cabinet house my personal hygiene items and some dog medicines. They are eye level and lower, so I have no need to look beyond them to the highest shelf.

Jim's things occupied a lower shelf when he was alive. After he died, I decided to clean the items out of the cabinet, but instead ended up moving the shaving cream, razor, aftershave, men's hairspray, cologne and other items to that top shelf.

At first I took comfort in

knowing they were there, as if they would be ready for him when he came home. I knew in my heart he would never come home, but in early stages of grief, you just pray you're living a nightmare that you'll wake up from and discover that everything is still as it should be.

So permanent changes are out of the question.

After a while, I just got used to the things being on the top shelf and there was no real reason to sort through them or throw them out. They weren't in my way, and on some level, they gave me a little comfort.

But now their existence is nagging at me. I fear that on some level, the shelf and its content have become a memorial or shrine of sorts.

I think you have to be careful about memorials and shrines. They have a way of spreading and eventually taking over your personal space, and encroaching on your identity. I don't want to be defined that way.

There is nothing wrong

with having reminders of a loved one, especially if they give you comfort or bring up a happy or important time in your and your loved one's life. But I think the role of what we hang onto needs to be clear.

And what is clear to me about Jim's items on the top shelf is that I am avoiding dealing with them. They're not things I would use. Nor would anyone else. They really are not things that defined Jim. They are hygiene products. And most likely expired and past their usefulness by now.

They're personal, but not as personal as clothes or pocket junk. Not as personal as music or favorite books or movies. Not as personal as daily routines and people who are important to us. Not as personal as the wedding band I still wear. Not as personal as what we meant — and mean — to each other.

But somehow thinking about cleaning out that shelf and taking over the space for my own stuff is another job at the nightmare that is my reality and has been since Jim's death. It confirms I no longer share physical space with my beloved spouse.

Yet I know I have to do

something with that shelf's contents soon. I am moving beyond such things, and continuing to move forward requires me to take care of this and a few other things.

So I have a plan. I'm going to clean out the whole unit and rearrange it. The linen closet and the medicine cabinet will be cleaned out and reorganized, and I think I can throw out the content of that top shelf as part of a larger purge of unwanted and unused items.

I will feel better when I have taken care of this task, and I think it will give me courage to face other projects. It may hurt a little, but sometimes there has to be pain before there can be healing.

As a longtime employee of the Bangor Daily News, Julie Harris has served many roles over the years, but she now has her dream job as community editor. She lives in Hermon with her four Brittany dogs: Sassy, Bullet, Thistle and Quincy, who keep her busy in various dog sports. She was widowed at age 51 when her husband, Jim, died of pancreatic cancer. Follow her blog at [curves.bangor-dailynews.com](http://curves.bangor-dailynews.com).



JULIE HARRIS



**KOHL'S**  
Cares  
ABOUT **ME**

*Growing Healthy Communities*

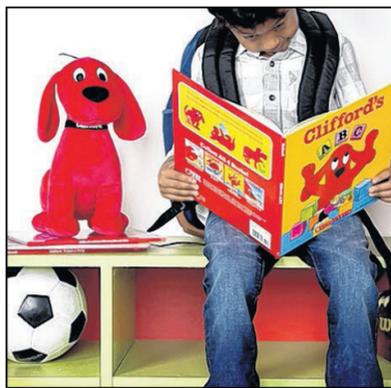
**A PROGRAM TO  
SUPPORT THE HEALTH  
AND WELLNESS OF  
MAINE FAMILIES**

*Our goal is to increase access to healthy foods for Maine kids through community and school gardens.*

Partnering with Kohl's Cares, Seabrook Valley Health (SVH) encourages Maine families and youth to discover the benefits of healthy eating through local farming and gardening.

SVH is passionate about helping nurture new and innovative programs for local schools, area farms and community groups.

**To learn more about the Kohl's Cares About ME program and how to get involved yourself, please visit [www.KohlsCaresAboutME.org](http://www.KohlsCaresAboutME.org)**



Kohl's Cares provides Maine families with an easy way to give back to Maine communities and support Maine kids' health!

Visit the Kohl's Cares website to learn more about Kohl's community giving efforts across the country and to view and purchase the Kohl's Cares merchandise.

"One hundred percent of the net profit from Kohl's Cares merchandise sold in local Kohl's stores supports the Kohl's Cares About ME program"

**SVH**  
SEABROOK VALLEY HEALTH  
— EMHS MEMBER  
[SEABROOKVALLEYHEALTH.ORG](http://SEABROOKVALLEYHEALTH.ORG)



# Directory

Continued from Page C1

by the Bangor-based Eastern Area Agency on Aging with additional support from the former Hammond Street Senior Center and other sponsors, the compiled businesses and service providers are all based in Bangor and 15 communities in the surrounding area.

It took nearly three years to complete the project, Davidoff said, and the combined efforts of Gateway Senior volunteers, the University of Maine Center on Aging and various student groups from UMaine, who earned academic credit for their involvement. For the most part, she said, appropriate entries and supporting information were compiled using online searches.

Of course, one benefit of online information over print is the ability to keep it up to date. Won't the Senior Yellow Pages be quickly outdated? Yes, Davidoff agreed — that's why the group has decided to post the information online as well, where it can easily be refreshed as needed.

"It'll be on the web in October," Davidoff said, at [www.senioryellowpages.org](http://www.senioryellowpages.org), which is not yet active. She anticipates there will

be future paper editions as well but will not predict when.

Davidoff is not aware of any other local senior advocacy groups, in Maine or beyond, that have undertaken a similar project. If other groups are interested in compiling a Senior Yellow Pages for their own regions, she said, Gateway Seniors will be glad to share their experience.

At Eastern Area Agency on Aging, Executive Director Dyan Walsh said the Senior Yellow Pages fills an important niche in the area, providing essential information to non-computer-savvy seniors who prefer to contact a business directly, by phone, rather than working through a clearinghouse service like EAAA or the statewide 2-1-1 program.

EAAA has already compiled a list of area residents who are waiting to get their hands on the new Senior Yellow Pages. Others who would like a copy may contact the agency at 207-941-2865 or contact their local library.

Gateway Seniors Without Walls was founded in 2013 in affiliation with the University of Maine Center on Aging. Its mission is twofold: to sponsor a variety of social activities, including films, lectures and fitness classes, and to publicize community services for seniors.

# Haskell

Continued from Page C1

for several years now. We delight in knowing they've tested the waters of their relationship and are moving forward together with their eyes and hearts open.

Marriage is not to be entered into unadvisedly or lightly, but reverently, deliberately and in accordance with the purposes for which it was instituted by God, if we are to believe the time-tested words of the marriage

service in the Episcopal Book of Common Prayer. Despite distressing divorce statistics and the unhappy outcomes of so many marriages, I find joy and hope in the ongoing commitments we make to each other. I am grateful for the friends who have forged long, enduring marriages that light the way for others to follow, even as we sometimes falter, stumble, fail and, blessedly, start over.

Read more of Meg Haskell at [livingitforward.bangor-dailynews.com](http://livingitforward.bangor-dailynews.com).