

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

3-31-2020

Giving back during the COVID-19 pandemic

Kenneth P. Serbin
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

Digital USD Citation

Serbin, Kenneth P., "Giving back during the COVID-19 pandemic" (2020). *At Risk for Huntington's Disease*. 288.

<https://digital.sandiego.edu/huntingtons/288>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

Blog Archive

▶ 2021 (12)

▼ 2020 (16)

▶ December (1)

▶ November (3)

▶ October (1)

▶ August (1)

▶ July (1)

▶ May (1)

▶ April (1)

▼ March (3)

[Giving back during the COVID-19 pandemic](#)

[In times of crisis,](#)

[Huntington's and other chronic...](#)

[CHDI head scientist](#)

[Pacifi: 'hang on in the lear...](#)

▶ February (3)

▶ January (1)

▶ 2019 (19)

▶ 2018 (16)

▶ 2017 (14)

▶ 2016 (13)

▶ 2015 (24)

▶ 2014 (24)

▶ 2013 (30)

▶ 2012 (26)

▶ 2011 (33)

▶ 2010 (26)

▶ 2009 (21)


▶ 2008 (7)

▶ 2007 (7)

▶ 2006 (4)

▶ 2005 (17)

About Me

 [GENE VERITAS](#)

[View my complete profile](#)

HD Links

TUESDAY, MARCH 31, 2020

Giving back during the COVID-19 pandemic

Many advocates for Huntington's and other rare diseases work passionately and selflessly for their causes.

Now, as the coronavirus pandemic rages, more and more people around the globe want to give back.

We are all witnessing the testimonies of the doctors, nurses, and other healthcare workers who offer front-line care for the patients hit with COVID-19, the disease caused by the virus.

As a Huntington's gene carrier who lost his mother to the malady, I, too, want to help – in part because the crisis has postponed or [forced online](#) so many aspects of the HD cause (more on this in an upcoming article).

HD activists *can* and *should* do their part to help alleviate this crisis!

Preparing for a surge of patients

Worried about the flood of reports about shortages of personal protective equipment (PPE), I reached out to [Yale University](#) class of 1982 colleague and freshman roommate [Peter S. Kieffer, M.D.](#), an emergency room pediatrician, to see if I could help, perhaps by organizing an online campaign to support him and his institution. Dr. Kieffer works at [HSHS St. John's Hospital](#) in Springfield, IL. An assistant professor at the [Southern Illinois University School of Medicine](#), he also advocates for the chronically mentally ill through [Independence Center](#).

In 2014, after decades out of touch, Dr. Kieffer wrote in an e-mail that he had discovered this blog and my family's struggle against HD.

“My heart goes out to you and your family as I have been long aware of the challenges of Huntington's disease, its genetic transmission, and the implications of early testing but have never known anyone personally with the diagnosis,” Dr. Kieffer wrote.

Since then, he and his family have donated generously to the [Serbin Family Team](#) in the annual Hope Walk of the San Diego Chapter of the [Huntington's Disease Society of America](#) (HDSA). Several years ago, they visited us during their vacation in the area.

In his response to my March 28 e-mail, Dr. Kieffer explained that “physicians in rural Illinois have had more time to prepare for COVID-19 than our colleagues in big cities.”

“Numbers were small, now cases are becoming more frequent, and we are preparing for a surge in the next few weeks which could very easily surpass the ICU bed and ventilator capacity of our two hospitals,” he wrote. “However,

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
[HD Free with PGD!](#)
[Stanford HOPES](#)
[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

Governor [J. B.] Pritzker's early shutdown may help blunt that curve. Although COVID-19 typically sickens children with less severity, they could still pass it to a white-haired pediatrician like myself! Fortunately, we still have enough PPE for what we need.”

So far, Dr. Kieffer has treated a young child who was a “Patient Under Investigation,” although tests have not yet confirmed COVID-19 in any of his patients, he wrote in an e-mail today.

Dr. Kieffer agreed to contact me should his institution need aid. I know that I personally cannot send PPE or medical equipment, but raising awareness about the local predicament and raising funds could be a way to assist.



Peter S. Kieffer, M.D. (photo by Southern Illinois University School of Medicine)

Donating critically needed blood

There are other ways I - and you - can help *now*.

After seeing an [American Red Cross blood drive](#) appeal on TV a couple weeks ago, I scheduled a donation for March 30.

Last week, I suspended my minimal meat diet to raise the iron levels in my blood, as recommended by a Red Cross employee, who set me up for a “[power red](#)” donation (double the number of red blood cells).

That employee also told me of a critical shortage of blood, as reported by the Red Cross and in the media ([click here](#) to read more).

At the donation center, an employee took my temperature at the door, to make sure I had no fever and, therefore, possible COVID-19 symptoms. Donors were spaced about eight feet apart, to avoid contamination, and the nurses and other workers wore not only the typical gloves, but also masks.

Unfortunately, in a pre-donation pin-prick blood test, I fell just shy of the necessary iron level for a power red.

However, I was able to make a simple “whole blood” donation.



Gene Veritas, aka Kenneth P. Serbin, at an American Red Cross blood donation center in San Diego (photo by Gene Veritas)

Running risks for the common good

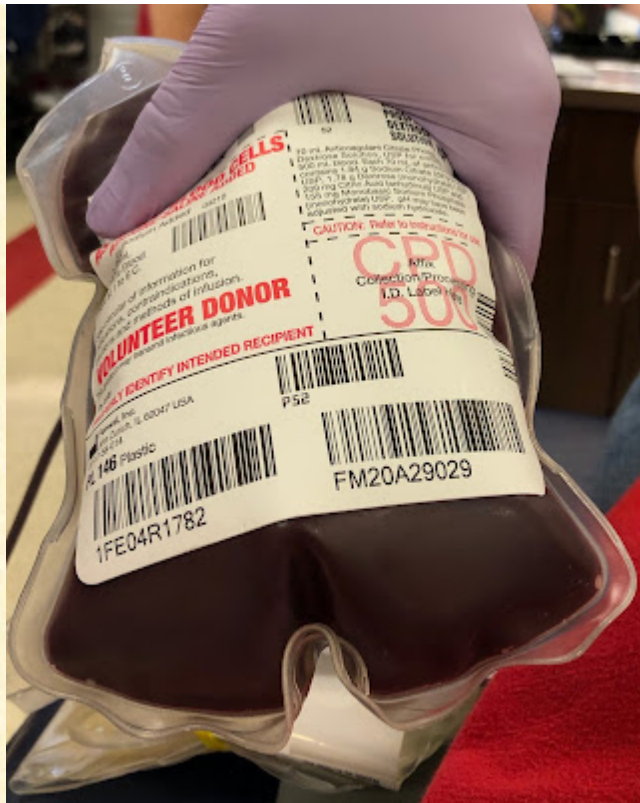
On the way home I thought: in any public place, we all run the potential risk of contracting the coronavirus, even at a facility like the Red Cross.

I washed my hands very thoroughly, twice at the facility, then again at home. None of the donors, nor I, wore a mask. However, I may on future trips to public places, given the increasing number of reports about their effectiveness in blocking droplets that might contain the virus.

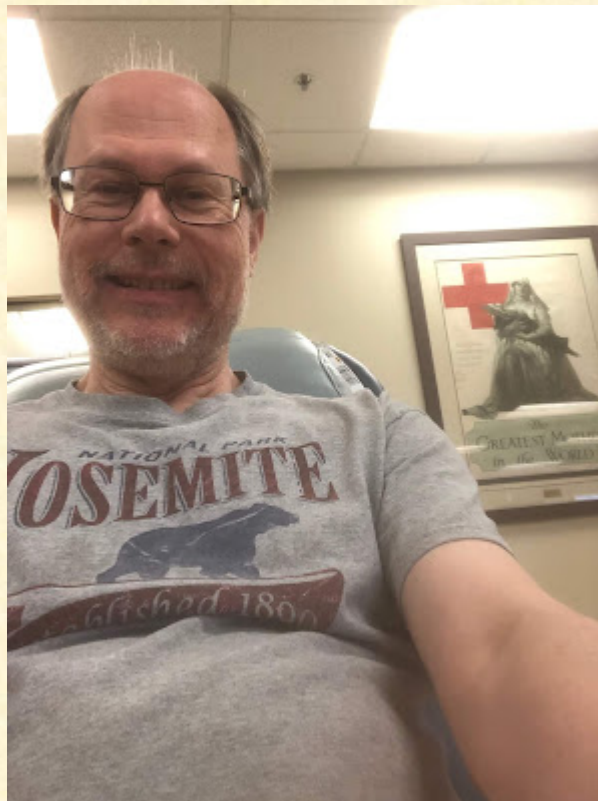
Like so many other HD gene carriers, I’ve spent many moments monitoring myself for symptoms. Now, I’ve started doing that for the virus.


However, physicians like Dr. Kieffer, first responders, grocery store workers, and so many others risk their health daily for the common good.

We all need to embrace the spirit of Dr. Kieffer’s words to me, echoing one of the signs at the Red Cross: “Thanks so much for your life-giving donation!”



Above, Gene Veritas' blood pack, and below, Gene Veritas in a donor chair at the American Red Cross (photos by Gene Veritas)



Posted by [Gene Veritas](#) at [10:57 PM](#)     

Labels: [advocates](#) , [American Red Cross](#) , [blood shortage](#) , [coronavirus](#) , [COVID-19](#) , [emergency room](#) , [HD gene carrier](#) , [HSHS St. John's Hospital](#) , [Huntington's disease](#) , [pandemic](#) , [pediatrician](#) , [Peter Kieffer](#) , [rare diseases](#) , [Yale](#)

No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)
