

July 26, 2016

Will Cook, President and CEO, University of Colorado Hospital
Peter Buttrick, MD, Division Head of Cardiology
David A. Schwartz, MD, Department of Medicine Chair
John J. Reilly, Jr. MD, Vice Chancellor for the Office of Health Affairs
Mark Earnest, MD, PhD, Division Head of General Internal Medicine

University of Colorado Hospital
12605 E 16th Ave
Aurora, CO 80045

To: Mr. Cook, Dr. Buttrick, Dr. Schwartz, Dr. Reilly, and Dr. Earnest,

We are writing to express our extreme disappointment over the sudden closing of Dr. Jill Schofield's dysautonomia and antiphospholipid syndrome (APS) clinic within the Cardiac and Vascular Center at the University of Colorado Hospital (UCH) on July 18, 2016. We would like to address several points with you:

- We need dysautonomia specialists and/or a dysautonomia clinic in Colorado;
- Dr. Schofield was providing outstanding care for patients with complex medical conditions; and
- It is completely unacceptable to close this clinic with no notice to patients, no notice to Dr. Schofield, and no plan in place to transition patient care to other providers. We are shocked and appalled that UCH would jeopardize patient safety with such a reckless decision and treat one of your own physicians and medical school graduates so unprofessionally.

Dysautonomia is common and not rare, as many people mistakenly think. Patients with these chronic conditions have seen many specialists and struggled for years to find a diagnosis and appropriate treatment. Some hospitals in the U.S. have full Dysautonomia/Autonomic Disorders Clinics employing multiple physicians such as Harvard, Vanderbilt, Stanford, Cleveland Clinic, Mayo Clinic, Duke, University of Texas Southwestern, Children's Hospital of Philadelphia, and Children's National Medical Center. Many other teaching hospitals have physicians specializing in treating autonomic disorders within various specialties or in coordinated clinics. However, if you look at the extensive physician list on the Dysautonomia International website (www.dysautonomiainternational.org), you will note that Dr. Schofield was the only physician listed in Colorado and for the entire Mountain West. Prior to Dr. Schofield's arrival, most Colorado patients struggled to find physicians who understand autonomic disorders and were often still searching for diagnoses for their wide ranging symptoms. Those who were fortunate enough to know what they needed traveled to one of the autonomic clinics out of state, if they could afford to do so.

We need the UCH administration to recognize the great need to increase, not decrease, the care for dysautonomia patients in Colorado. It is also our understanding that an Autonomic Disorders Clinic had previously been proposed by a group of physicians at the Children's Hospital of Colorado (Children's), but denied by the administration. We believe there is a need for this type of clinic at UCH and Children's. For a hospital system of this caliber, we believe it is a serious oversight to not provide quality care for

patients with autonomic disorders. These clinics are economically viable when run properly, as demonstrated by numerous clinics across the U.S. Dysautonomia International is a 501(c)3 non-profit that has assisted several other hospital systems in setting up successful autonomic disorders clinics, and they can be of assistance to UCH too.

Dr. Schofield has an interest in this under-represented medical field and was utilizing her multidisciplinary training to provide invaluable care. She is in very high demand, as evidenced by the one-year wait list for new patients. She significantly improved the quality-of-life for many patients and is held in high regard by her patients and her peers. She handled very complex cases and worked with physicians across many departments at UCH. She was up-to-date on the latest treatments, which were individualized to each patient, from non-pharmacological treatments to immunotherapy, and everything in between. As patients, we know the UCH Mission, Vision, and Values, and Dr. Schofield embodied these fully: "Mission: We improve lives. In big ways through learning, healing and discovery. In small, personal ways through human connection. But in all ways, we improve lives. Vision: From health care to health. Values: Patients first, Integrity, Excellence." We would like to see the administration act in accordance with the UCH Mission, Vision, and Values on behalf of dysautonomia and APS patients.

Dr. Schofield had recently organized monthly multidisciplinary dysautonomia meetings that included providers from Children's and UCH in pediatric and adult gastroenterology, EP Cardiology, allergy and immunology, pain, psychology, genetics, and multiple different neurology providers including neuroepilepsy, headache, neurovirology and general neurology. This was an important step in increasing the knowledge base for dysautonomia at both campuses, something that the patient community desperately needs. She also spent the weekend of July 15-17, 2016 at an international conference on autonomic disorders in Washington, DC, where she was invited to present her research and clinical expertise to an audience of experts from Mayo Clinic, NIH, Yale, Johns Hopkins, Vanderbilt, and elsewhere. As you can image, we were shocked to hear that she arrived at work on Monday, July 18 to find out that her clinic had been closed without any advance notice.

There has been a huge outcry among the patient community over the abrupt elimination of her position at UCH. As mentioned above, we need more physicians treating dysautonomia patients, not less. We are upset that her position was eliminated, especially the way in which it was handled. Patients were given no warning, no continuation of care, and no explanation. The receptionists calling to cancel appointments told patients to follow up with their primary care provider, one of the cardiology physician assistants, or seek care out of state. For many patients, these are not acceptable or realistic alternatives and they risk negative consequences due to the inadequate continuation of care. UCH's decision to abruptly close a clinic without any advance notice to patients and without an adequate transition plan suggests a callous disregard for patient safety - not the "patients first" value UCH purports to embody.

The patients who were finally thriving under the care of Dr. Schofield feel they have lost a literal lifeline and that this is the antithesis of good medical care. Other patients were desperately waiting their turn for their first appointment. This whole situation reflects very poorly on UCH and significantly hurts Dr. Schofield professionally and personally.

We were fortunate to have Dr. Schofield providing care in this area. Sadly, it appears UCH does not recognize this need and is not willing to support experts like Dr. Schofield practicing here.

We respectfully ask you to address the following:

- reconsider your decision and allow Dr. Schofield to resume seeing patients at UCH OR immediately put together a team of doctors capable of managing Dr. Schofield's autoimmune/dysautonomia patients, so that these complex patients are not abandoned and left without adequate medical care;
- continue infusion treatments for Dr. Schofield's patients who already have insurance approval, until patients can find another infusion facility;
- expedite medical records requests for Dr. Schofield's patients who are attempting to transfer care to other providers - waiting weeks for medical records is not acceptable for patients who are in the middle of a course of immunotherapy or who are on carefully managed APS therapies;
- provide Dr. Schofield's patients with an apology and a clear explanation for the abrupt elimination of her clinic without notice; and
- consider establishing an interdisciplinary Autonomic Disorders Clinic that would extend the reach of this care at both UCH and Children's.

We request a written response to the Colorado based Dysautonomia International volunteer advocates, Ellen Heyd and Yael Cohen (see attachment for contact information).

Thank you for your consideration,

Dr. Schofield's Patients and Caregivers
(Names, addresses, and additional comments attached)