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August 31, 2017

Francis S. Collins, MD, PhD
Director
National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892
Email: Francis.Collins@nih.hhs.gov

Dear Dr. Collins,

The Union for Affordable Cancer Treatment (UACT) is a union of people affected by cancer, their family members and friends, people who take care of people with cancer, health care professionals and cancer researchers committed to increasing access to effective cancer treatment and care. We are particularly concerned about the rapidly escalating cost of cancer medication and seek to fight for cancer treatment and care to be affordable and available, everywhere, for everyone who needs it.

We are writing to ask the National Institutes of Health (NIH) to create a page on the NIH web site that provides the details of every grant, patent, patent license, CRADA and other types of agreements as well as every NIH expenditure that are related to the development of CAR T treatments.

Under 15 U.S.C. § 3710a(c)(6), the NIH is required to keep a record of CRADAs entered into: “Each agency shall maintain a record of all agreements entered into under this section.”

We need access to authoritative versions of this information to engage in informed discussions with the companies selling CAR T treatments on pricing and affordability issues.

Also, please send us a list of the countries where the NIH will file (or has filed) for patent protection on the many patents on CAR T owned by the NIH.

Finally, will the NIH enter into discussions with the Medicines Patent Pool to provide licenses to the CAR T patents in developing countries?

We look forward to receiving your response to these requests and concerns. Thank you.

Sincerely,

Manon Ress, Acting Director, UACT
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Jordan Donn Jarvis, Member, UACT Board of Directors

Ophira Ginsburg, MD, Member, UACT Expert Advisory Board

Gilberto de Lima Lopes Jr., MD, MBA, FAMS, Member, UACT Expert Advisory Board

Ruth Lopert, MD, Member, UACT Expert Advisory Board

Ilze Aiselniece, Member, UACT Organizing Committee

Cc: Senator Lamar Alexander
Senator Roy Blunt
Senator Patty Murray
Senator John Kennedy
Senator Bernie Sanders
Senator Al Franken
Senator Angus King
Senator Dick Durbin
Representative Lloyd Doggett
Representative Jan Schakowsky