

External Evaluations

Chan Zuckerberg Initiative (CZI) Award

PSC Partners is honored to have been one of the thirty rare disease organizations to be selected from 287 applications from 43 states. We were selected based upon our patient led approach. Here is a link to the article about the program and awards:

<https://chanzuckerberg.com/newsroom/chan-zuckerberg-initiative-awards-13-5-million-to-drive-progress-against-rare-diseases/>

Here is a link to the video and the list of recipients:

<https://chanzuckerberg.com/science/programs-resources/rareasone/>

Patient Friendly Drug Development (PFDD) Meeting

The FDA awarded PSC Partners the opportunity to host an externally led meeting in the fall of 2020.

Below is an overview of what a PFDD meeting is.

PFDD Abstract:

The U.S. Food and Drug Administration (FDA) has multiple mechanisms for its regulators and staff to interact with patients – but none quite like its novel Patient-Focused Drug Development (PFDD) initiative. FDA established the PFDD initiative to more systematically obtain the patient perspective on specific diseases and their currently available treatments. Since the initiative's inception in 2012, FDA has held 24 PFDD meetings, covering a range of disease areas and hearing directly from thousands of patients and caregivers. FDA's PFDD meetings have also provided key stakeholders, including patient advocates, researchers, drug developers, healthcare providers, and other government officials, an opportunity to hear the patient's voice. The lessons learned include but are not limited to specific experiences that matter most to patients, patient perspectives on meaningful treatment benefits and how patients want to be engaged in the drug development process. FDA recognizes that FDA-led PFDD meetings alone cannot address the gaps in information on the patient perspective. Further enhancing the incorporation of the patient's voice in drug development and evaluation continues to be a priority for FDA.

Great Nonprofits

We were designated as a Top-Rated 2019 Great Nonprofit.

Here is the link to the reviews:

<https://greatnonprofits.org/org/psc-partners-seeking-a-cure>