

## **DGIM Project Summary**

**Name of Project:** Improving the transfer from pediatric to adult care for young adults with childhood-onset chronic diseases

**Investigator(s):** Megie Okumura, MD, [megumi.okumura@ucsf.edu](mailto:megumi.okumura@ucsf.edu), (PI, primary contact) and Erica Lawson, MD (Co-I), [erica.lawson@ucsf.edu](mailto:erica.lawson@ucsf.edu)

**Research question(s):** How will a structured transfer summary developed in conjunction with pediatric subspecialists assist in the transfer of care from pediatric to adult primary care providers. In what ways will educational materials assist adult primary care providers to care for relatively rare, but complex medical conditions that originate in childhood?

**Brief Background/Significance:** Young adults with childhood-onset chronic diseases often fail to establish care after leaving pediatrics, putting patients at risk for disease progression. Once young adults with childhood-onset conditions do transfer to adult-oriented care, adult providers often feel unprepared to manage their medical conditions. National data demonstrates that, among adult providers, receipt of an accurate medical summary prior to the first visit is the most critical component of pediatric-to-adult handoffs. This proposal aims to (1) improve continuity of care and information transfer during the transition from pediatric to adult care, and (2) empower adult primary care providers with tools, knowledge and support to ensure that patients and providers can build a future medical home together.

**Inclusion/exclusion criteria:** *Provider Inclusion:* UCSF adult primary care provider  
*Patient Inclusion:* Insurance that allows patient to be seen at DGIM, seen by pediatric primary care/subspecialty provider at UCSF in past year, age 19 or older, and has not been seen in UCSF adult primary care system. *Exclusion:* Non-English speaking, wards of state, or incarcerated

**Method of contact/recruitment:** For providers, the study team will reach out by email. For patients, the research coordinator will contact them by phone after their first adult appointment to inquire whether they would like to give feedback on their transfer experience.

**Benefits/burden for participants:** The survey and interviews may take time (15min, 45 min for interview). Some survey questions could make patients uncomfortable, but the person is free to decline to answer any questions and can stop the survey/interview at any time. The surveys/interviews will help inform the program improvement process through feedback from providers and patients. The investigators think there is minimal risk to participants, and the potential gain to improve the transfer process for young adults outweighs risk of discomfort.

**Any benefits or burden to DGIM practitioners?** Based on input from DGIM practitioners, this project will offer tailored lectures and information on primary care delivery for more common conditions, including congenital heart disease, autism/developmental disability, childhood-onset rheumatologic conditions, and hematological conditions.

**Timeline for recruitment:** Start recruiting, 11/15/18; Stop recruiting, 6/30/19

**Funding source:** Mt. Zion Health Fund, HRSA/AAP.

**Potential for DGIM collaborators?** We've worked with Gerri Collins-Bride and Nicole Appelle on the process. We welcome any resident, fellow or faculty member interested.

**Do you agree to notify us when recruitment is completed?** Yes

**Date form completed:** 11/7/18