Massachusetts General Hospital
Founding Member, Mass General Brigham

The Maxwell & Eleanor Blum
Patient and Family Learning Center

Coordinating Care for a Person with a Rare Genetic Disorder

Date: Wednesday, February 12, 2025

Time: 12–1 pm (Eastern Time)

When a genetic disorder is identified in a person, there may be a sense of relief at the end of a diagnostic odyssey. However, there is often no playbook or manual to guide the person, their family, and providers. Fortunately, Patient Advocacy Groups (PAGs) or Disease Advocacy Organizations (DAOs) provide a community to fill many gaps. This talk will hopefully be received as a pep talk to encourage people to coordinate care even when a person is unique.

Featured Speaker: Angela E. Lin, MD, FACMG

Dr. Lin is a medical geneticist at Mass General for Children in Boston, Massachusetts who is passionate about the multispecialty care of people with rare syndromes. She is the co-director of the MGH Turner Syndrome Clinic and MGH Myhre Syndrome Clinic. Dr. Lin also sees patients in the Hereditary Hemorrhagic Telangiectasia (HHT) Center. She has additional interests in Sotos syndrome, Costello syndrome, CHARGE syndrome, and the MN1 C-Terminal Truncation syndrome. Regardless of the disorder, families and providers benefit from communication within their team and networking outside to expand their knowledge base.

- This program is free and open to Mass General patients, families, staff, and the general public.
- To attend this program, click on the link or scan the QR code: https://partners.zoom.us/j/87958487056

For more information, call 617-724-7352 or email PFLC@partners.org

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Blum Center Program Schedule

Scan this QR code with your phone's camera
to see our program schedule online

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