

Rare Disease Challenges: Support for Patients & Families
Resources to Accompany the Video

Watch this Video with the QR code below, or at: www.youtube.com/user/aHUSclinical

Download the video's **Resource List** at: www.bit.ly/RareDiseaseResources



*A chronic illness or rare disease diagnosis affects all individuals and groups associated with the patient. Managing medical aspects may impact family dynamics, personal relationships, professional or work areas, and other interactions across all facets of everyday life. This list provides links to organizations and resources that offer assistance to those challenged with rare disease issues and concerns. Our **Patient & Family Assistance Tips** suggest ideas for friends, relatives, coworkers, or community members to offer support.*

This video and its resource list are Rare Disease Advocacy Efforts of the Atypical HUS Foundation at www.atypicalhus.org



CAREGIVERS – ADVOCACY AND SUPPORT

COPING with SOCIAL and EMOTIONAL ISSUES

PATIENT ASSISTANCE PROGRAMS

AGE SPECIFIC RESOURCES
Children, Teens, Seniors

THERAPY INFORMATION AND ORGANIZATIONS

RARE DISEASE ORGANIZATIONS

RARE DISEASE ADVOCACY

ORGANIZATIONS FOR UNDIAGNOSED OR UNNAMED SYNDROMES

OTHER RESOURCES for Patients, Families, and Caregivers

TOOLS – Organizational Management

PATIENT & FAMILY ASSISTANCE TIPS

(How Relatives, Friends, Neighbors, Coworkers and Others Community Members Can Help) Suggestions Specific to Patients, Siblings, Caregivers, the Workplace and More Organizational Strategies (Accordion Files)