CLICK HERE TO JOIN THE CONFERENCE LIVE STREAM 9AM - 5:30PM ET
PASSCODE: SPATA (all caps)

RESOURCES

We've put together a variety of resources we think you might find helpful. Please click on each item and it will open up as a separate website or as a PDF.

CAREGIVER BURNOUT
A quick guide to Caregiver Burnout. Caregiver burnout is a state of physical, emotional, and mental exhaustion that occurs when a person provides long-term care for a loved one.

ONCE UPON A GENE - RARE DISEASE PODCAST
Effie Parks has become a guiding light in the rare disease community following her son Ford's diagnosis with CTNNB1 syndrome. She transformed her family's journey into a crusade for advocacy, support, and empowerment for families navigating similar challenges. With a mission to leave the world better than she found it, Effie is dedicated to fostering a more informed and empathetic environment for those impacted by rare diseases.

NORD STATE RESOURCE CENTER FOR RARE DISEASES
NORD's State Resource Center contains information on organizations that offer free or low-cost programs and services for individuals impacted by rare disease.

DANNY DID FOUNDATION FOR SUDEP
Founded by Chicagoans Mike and Mariann Stanton after the Sudden Unexpected Death in Epilepsy (SUDEP) of their son Danny just before his fifth birthday. We are dedicated in our mission to prevent deaths caused by seizures.

PARKINSON & MOVEMENT DISORDER SOCIETY
Help your patients and their families better understand their disease, symptoms, and options. Each topic can be translated into 100+ languages and conveniently printed or

MEJO MEDICAL HISTORY ORGANIZATION APP

Mejo stores all health information in one place. Use it to seamlessly communicate important health + care information to family members, medical professionals, and schools. This innovative tool simplifies caregiving, saving our users valuable time by acting as their digital assistant.

10 TIPS FOR NEWLY DIAGNOSED RARE DISEASE PATIENTS AND FAMILIES

Youtube video providing tips for newly diagnosed patients and their families. The video includes further information on recommendations including giving yourself time to adjust, connecting with others and learning about your rare diseases.

TRANSITIONING TO ADULT CARE

As rare disease patients approach adulthood, they face the transition from parent-supervised pediatric care to more independent adult models, taking ownership of their own care. This change can seem daunting for patients and parents, especially when dealing with rare disorders that involve multiple specialists that may be part of a care team. This webinar shows viewers how to plan for this change and shares the first-hand experience of a family living with congenital bilateral perisylvian syndrome (CBPS).

THE RARE SIBLING EXPERIENCE

The impact of a rare disease extends beyond the patient and is interwoven into the entire family dynamic. Siblings of rare disease patients often face personal challenges inside and outside of the home. Guidance and nurturing can empower unaffected sibs to be supportive members of the family, while maintaining their unique identities.

QUESTIONS?

REACH OUT TO MARIAH (FOUNDER, THE SPATA FOUNDATION)

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