



Mental Health & Prevention Fact Sheet

Supporting Families & Professionals in Rare Disease Communities

The E.WE Foundation | PO Box 6391, Huntsville, AL 35813 | www.theewefoundation.org

WHY MENTAL HEALTH MATTERS

- Families of individuals with rare or complex medical conditions face unique emotional challenges.
- Strong mental health reduces caregiver burnout, strengthens advocacy skills, and improves overall family well-being.
- Early awareness, support, and intervention can prevent long-term stress and trauma.

SIGNS TO WATCH FOR

Children & Adolescents:

- Changes in behavior or mood
- Withdrawal from friends or activities
- Trouble concentrating or sleeping

Caregivers & Parents:

- Persistent stress or fatigue
- Difficulty managing daily responsibilities
- Feelings of anxiety, sadness, or frustration

TIPS FOR EMOTIONAL WELLNESS

- Maintain routines and structure
- Build peer and community support networks
- Seek professional counseling when needed
- Practice self-care: sleep, nutrition, exercise, mindfulness
- Encourage open communication within the family

Visit E.WE Mental Health Resource Center

Explore tools, guides, and trusted resources designed to support both families and professionals.

Learning Opportunities

For Families:

- Coping strategies workshops
- Peer support
- Grief and bereavement sessions

For Professionals:

- Youth Mental Health First Aid (YMHFA) certification – National Council for Mental Wellbeing (*also available for families*)
- CEU-accredited LEAP workshops on advocacy, health literacy, and mental health support
- Trauma-informed care and rare disease awareness training

Local & National Resources

Local (North Alabama):

- The Enrichment Center – School-based counseling
- National Children's Advocacy Center – Trauma & parenting programs
- Crisis Services of North Alabama – 24/7 crisis support
- NAMI Huntsville – Peer support & education

National & Online:

- MentalHealth.gov – Parents & Caregivers
- Child Mind Institute Resources
- SAMHSA – How to Help Your Child Cope
- National Suicide & Crisis Lifeline: **988** (24/7 support)

Get Help Today

- Seek professional support early.
- Connect with local and national mental health resources.