

BEYOND THE DIAGNOSIS

EMOTIONAL, SOCIAL, AND SYSTEMIC CHALLENGES WITHIN THE RARE DISEASE COMMUNITY

1.5 HOUR CE Credit (See Page 2)

Hosted by Give an Hour, and Supported by Alexion

Originally
Recorded:
May 6th
12:30 ET



MODULE 4: ISOLATION TO CONNECTION: UNDERSTANDING RELATIONSHIP STRAIN IN RARE DISEASE

Description:

In this module, clinicians will explore how rare disease can reshape relational systems across the lifespan. Participants will examine common relational challenges, including social network contraction, sibling role complexity, anticipatory grief within families, and tensions between protection and autonomy. The session will also highlight ways mental health professionals can support clients in navigating relationship strain while fostering connection, communication, and relational resilience.

INSTRUCTORS:

Dr. Al Freedman

Psychologist, Educator, & Rare Disease Advocate

Ronda Thorington, LPC

Chronic Illness - Parent Coach



Al Freedman, PhD, is a psychologist, educator, and rare disease advocate with more than two decades of experience working with individuals and families affected by rare diseases and disabilities.

Dr. Al is inspired by his personal journey as the father of Jack, who lived with spinal muscular atrophy (SMA) for 26 years, as well as his professional training and experience as an educator to provide counseling and consultation. He works with families, advocacy organizations, pharmaceutical companies, healthcare organizations, and schools to create meaningful support systems and impactful change within the rare disease and disability communities.



Ronda Thorington, LPC, is a Licensed Professional Counselor with over 20 years of experience providing parent coaching and mental health care to children, families, and adults in private practice in Connecticut. She brings both clinical expertise and lived experience as a parent of a child with a rare disease, informing her work supporting families navigating complex medical and relational challenges.



Hosted on ZOOM- For system requirements please visit: [ZOOM WEBSITE](#)

Learning Objectives:



Identify common relational challenges experienced by persons living with rare disease and their families, including social isolation, family strain, anticipatory grief, and shifting family and caregiving roles.



Describe how rare disease can affect different relationship domains, including friendships, sibling relationships, romantic partnerships, and professional interactions.



Apply trauma-informed and relationally sensitive approaches to support clients experiencing isolation, relationship strain, or role changes related to rare disease.

COURSE COMPLETION AND CE INFORMATION

FOR GIVE AN HOUR MENTAL HEALTH PROFESSIONAL LIVE TRAINING & WORKSHOPS

Course completion requirements:

- For any general questions or concerns, including those related to accessibility, please contact: providerrelations@giveanhour.org.
- At the end of the training session, a link to the post-assessment will be shared in the Zoom chat. The link will also be sent via email the following day.
- Two unique codes will be shared at random times during the session. Please take note of these codes – they are required to complete the post-assessment.
- Licensed Mental Health Professionals must attend the entire course, pass the post-assessment with a score of 80% or higher, and complete a course evaluation to be eligible for CE credit. Once all items are completed, the certificate will be automatically available for download in the ProProfs system.
- Cancellation and refund policies do not apply to Give an Hour trainings, as all of our trainings are offered free of charge. If you are unable to attend, simply do not participate—no penalties will be incurred, and no further action is required.
- You must join the training through Zoom using a web browser or the app. Phone (audio-only) participants are not eligible for credit, as attendance cannot be tracked.

CE Statements:

- Give an Hour provider # 2097, is approved as an ACE provider to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Regulatory boards are the final authority on courses accepted for continuing education credit. ACE provider approval period: 04/30/2025– 04/30/2026. Social workers completing this course receive 1.5 cultural competence continuing education credit.
- Give an Hour has been approved by NBCC as an Approved Continuing Education Provider, ACEP No. 7552. Programs that do not qualify for NBCC credit are clearly identified. Give an Hour is solely responsible for all aspects of the programs
- Give an Hour is approved by the American Psychological Association to sponsor continuing education for psychologists. Give an Hour maintains responsibility for this program and its content.

For questions, grievances, or special accommodations, please contact us at providerrelations@giveanhour.org or 240-745-5641. You can also visit giveanhour.org or write to us at PO Box 1532, Clarksburg, MD 20871.



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TRAINING AGENDA

*FREE Virtual ON-DEMAND Training Hosted by
Give an Hour, and Supported by Alexion*



Originally
Recorded on
Wednesday
May 6th
12:30 ET

TRAINING AGENDA – Module 4

Isolation to Connection: Understanding Relationship Strain in Rare Disease

Date: Wednesday, 6th May 2026 | 12:30 PM – 2:00 PM ET

Duration: 90 minutes (1.5 CE credits)

Format: Live synchronous distance learning (non-interactive)

Instructors: Al Freedman, PhD & Ronda Thorington, LPC

12:30 – 12:40 | Welcome & Training Overview (10 min)

- **Welcome and speaker introductions**
- **Overview of module and relevance to clinical practice**
- **Review of learning objectives**
- **Framing:**
 - Rare disease as a relational and systemic experience
 - Why relationship strain is a central clinical concern
- **CE reminders**

12:40 – 1:05 | Identifying Relational Challenges in Rare Disease (25 min)

- **Social Isolation & Network Contraction**
 - Friendship drift, exhaustion from explaining illness
 - Accessibility and energy limitations shaping social participation
- **Family Strain & System Stress**
 - Caregiver burden and role overload
 - Emotional suppression and “holding it together” dynamics
- **Anticipatory Grief**
 - Ongoing grief related to uncertainty, progression, or potential loss that is held across the family system
 - Emotional withdrawal, hypervigilance, and tension within families
- **Shifting Roles & Caregiving Dynamics**
 - Parent-child role changes
 - Increased dependency vs push for autonomy
 - Role rigidity and imbalance over time

**Agenda subject to minor adjustments based
on presenter flow and audience needs.**

1:05 – 1:30 | Understanding Impact Across Relationship Domains (25 min)

- **Friendships & Social Relationships**
 - Changing relationships
 - Misunderstanding of invisible illness
 - Social withdrawal and identity loss
- **Sibling Relationships**
 - Guilt, invisibility, and role confusion
 - Early independence vs emotional neglect
 - Complexity of support vs burden
- **Romantic Partnerships**
 - Caregiving imbalance and shifting expectations
 - Emotional fatigue, resentment, and intimacy disruption
 - Potential for both strain and deepened connection
- **Family System (Extended & Immediate)**
 - Differing coping styles and belief systems
 - Tension around care decisions and understanding

1:30 – 1:55 | Clinical Application – Supporting Connection & Relational Resilience (25min)

- **Trauma-Informed Relational Lens**
 - Normalize chronic stress, ambiguity, and grief
 - Avoid pathologizing relational strain
- **Clinician Stance**
 - Lead with curiosity, humility, and transparency
 - Acknowledge knowledge gaps and collaborate with clients
- **Intervention Strategies**
 - Facilitate communication within families and couples
 - Parent Coaching - Chronic Illness
 - Support role renegotiation and boundary setting
 - Help clients identify and build support systems vs isolation
- **Reconnection & Resilience Building**
 - Encourage small, sustainable relational touchpoints
 - Support identity beyond illness
 - Increase visibility and inclusion of siblings and partners

1:55 – 2:00 | Closing & Key Takeaways (5 min)

- Summary of key concepts tied to learning objectives
- Final clinical reflections
- CE credit instructions
- Closing

Contact Info for Questions or Grievances

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