

BEYOND THE DIAGNOSIS

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



Originally
recorded on
Jan. 7th
12:30 PM

1.5 HOUR CE Credit Approved (See Page 2)

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



MODULE 2: BETWEEN ANSWERS & AMBIGUITY: COPING WITH THE UNKNOWN IN RARE

Description:

This module explores the psychological toll of prolonged ambiguity and the clinical skills required to meet it with steadiness and compassion. Drawing on insights from clinicians and lived-experience experts, participants will examine how uncertainty manifests at both macro and micro levels, from “Why me?” to “Will the nurse show up tonight?”, and how these layered stressors shape behavior, coping, and connection.

INSTRUCTORS:

Dr. Al Freedman
Psychologist, Educator, & Rare Disease Advocate

Cheryl Simoens M.A., B.A., C.C.C
Registered Psychotherapist | Complex Trauma | Rare Patient



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.



Cheryl Simoens, M.A., is a rare disease patient, advocate, and mental health professional living with nephropathic cystinosis. She holds a Master's Degree in Counselling Psychology and a Bachelor of Arts, and works with individuals ages 12 and older. Her areas of specialization include complex trauma and PTSD, anxiety disorders, shame and identity challenges, body image concerns, eating disorders, and the psychological impact of new diagnoses and chronic conditions.

Learning Objectives:



Describe the pervasive role of uncertainty in the rare disease experience, from macro-level existential questions to micro, day-to-day concerns about care, access, and stability.



Identify common psychological and physiological responses to prolonged uncertainty and how these responses manifest in individuals and family systems.



Differentiate between adaptive and maladaptive coping strategies individuals and caregivers use when facing ambiguous information or unpredictable outcomes.



Explore the clinical implications of “living between answers,” including how ambiguity can affect treatment adherence, trust in systems, and therapeutic engagement.



Examine the ethical, emotional, and relational dynamics surrounding clinical-trial participation, including clients' tolerance for risk, hope for breakthroughs, and navigation of uncertain outcomes.



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

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TRAINING AGENDA



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Training Agenda Module 2: Between Answers & Ambiguity: Coping with the Unknown in Rare Disease

Duration: 90 minutes

Format: On-Demand, Asynchronous Recorded on Zoom

Date: January 7, 2026 | Time: 12:30 – 2:00 PM ET

Speakers: Dr. Al Freedman

Cheryl Simoens, MA, BA, CCC

Moderator: Julie Wells | Give an Hour

12:30 – 12:35 | Welcome & Orientation

- Overview of the Rare Disease Mental Health Training Series
- CE requirements and learning objectives
- Framing the module: “Living Between Answers” as a central experience in rare disease

12:35 – 12:55 | How Uncertainty Presents in Rare Disease

- Macro-level uncertainty: existential questions (“Why me?”, “What does this mean for my family?”), identity shifts, meaning
- Micro-level uncertainty: day-to-day unpredictability
- Impact on roles and family dynamics

12:55 – 1:15 | Psychological & Physiological Responses to Chronic Uncertainty

- Emotional responses: anxiety, anticipatory grief, helplessness, irritability
- Physiological stress reactions: hypervigilance, sleep disruption, somatic tension, chronic activation
- Loss of perceived control: chronic unpredictability and fear-based cycles
- Family system responses: burnout, conflict, over-functioning, withdrawal

1:15 – 1:30 | Adaptive vs. Maladaptive Coping Strategies

- Adaptive coping: boundary-setting, paced planning, connection to community, meaning-making
- Maladaptive coping: avoidance, rumination, over-control, survival mode
- Lived-experience examples of coping across the rare journey

1:30 – 1:45 | Supporting Clients Clinically When They Are “Living Between Answers”

- How chronic ambiguity influences engagement in therapy and peer support (avoidance, crisis-driven communication, emotional flooding)
- Effects on trust: fear of bad news, medical/systemic mistrust, prior invalidation
- Clinician stance: modeling tolerance for uncertainty, attunement, steady presence, sequencing and collaborative decision-making

1:45 – 1:55 | Trauma-Informed, Resilience-Building & Meaning-Making Approaches

- Trauma-informed presence: attunement, pacing, collaborative transparency
- Resilience-building practices: emotional regulation, distress tolerance, micro-stabilization skills
- Meaning-making: narrative integration, identity reconstruction, reframing purpose
- Clinician self-regulation: maintaining presence when outcomes are unknown

1:55 – 2:00 | Ethical, Emotional & Relational Dynamics in Clinical Trials

- Balancing hope and risk when outcomes are uncertain
- Relational dynamics: family conflict, guilt, protective instincts
- Ethical considerations: informed consent, placebo concerns, unknown long-term outcomes

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

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.

Approved 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.

