

BEYOND THE DIAGNOSIS

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



Originally
recorded on
Nov. 12th
12:30 PM

1.5 HOUR CE Credit Approved

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

MODULE 1: THE FIRST STEP: TRAUMA, TRUST, AND RE- ORIENTING TO LIFE WITH RARE

Description:

This Training module will explore the often-overlooked emotional and psychological realities of living with a rare disease. While much attention is given to the medical side of these conditions, this training centers the human experience. The uncertainty, grief, and resilience that mark the diagnostic and care journey.

INSTRUCTORS:

Dr. Al Freedman, PhD

Psychologist, Educator, & Rare Disease Advocate

Katharine Provencher, MSW

Director of Advocacy and Community Engagement at
IgG4ward! Foundation



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.



Katharine Provencher, MSW serves as the Director of Patient Advocacy at IgG4ward! Foundation, a nonprofit dedicated to supporting and empowering individuals living with IgG4-Related Disease. She holds a Master's Degree in Social Work from the University of Connecticut and brings more than 18 years of experience as a School Social Worker with Springfield Public Schools. With expertise in trauma-informed practice, crisis intervention, and social justice, Katharine is passionate about advancing patient welfare, education, and mental health.

Learning Objectives:



Define the term rare disease and identify at least three examples relevant to clinical practice.



Describe the unique emotional impacts of the diagnostic journey, including experiences of delay, misdiagnosis, or lack of diagnosis.



Explain how rare disease can function as a form of trauma for people with the diagnosis, caregivers, and families.



Examine the psychological re-orientation that people with the diagnosis, caregivers, and families undergo when entering the rare disease world.



Identify the distinct mental health needs of individuals, caregivers, and families at various stages: newly diagnosed, those in long-term management, and those coping with loss.



Hosted on ZOOM- For system
requirements please visit: **ZOOM
WEBSITE**

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.
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TRAINING AGENDA



Originally
Recorded
Nov. 12th
12:30 PM

AGENDA – Module 1: The First Step: Trauma, Trust, and Re-Orienting to Life with Rare

Date: November 12 | 12:30 PM ET

Duration: 90 minutes (1.5 CE credits)

Format: Live synchronous distance learning

Instructors: Dr. Al Freedman & Katharine Provencher, MSW

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

- Welcome from Give an Hour and Alexion
- Introduce facilitators (Dr. Al Freedman & Katharine Provencher)
- Training overview and CE objectives
- Participant safety and emotional-care reminders

12:40 – 12:55 | Understanding “Rare” (15 min)

- What does “rare” mean in lived and clinical contexts
- Reframing rarity: isolation versus community
- When a condition becomes “not rare to us” – belonging to a hidden minority
- The clinician’s mindset: curiosity, humility, and willingness to learn

Key insight: Dr. Freedman frames rare disease as life-altering, communal, and “too big to do alone.”

12:55 – 1:20 | The Diagnostic Journey & Its Emotional Arc (25 min)

- Entering the Twilight Zone: The shock of abrupt diagnoses versus years-long diagnostic odysseys
- Medical systems and misdiagnosis – emotional toll of being the “educator”
- Loss of certainty, intrusion of medical systems into home life
- How trust in medicine is shaken or slowly rebuilt
- Variations in the trauma experience (newborn screening, delayed diagnosis, lifelong search)

Clinical framing: Normalize both acute and prolonged trauma responses; identify points for therapeutic support during diagnostic chaos.

1:20 – 1:35 | Trauma, Trust, and Hope after Diagnosis (15 min)

- How diagnosis functions as both relief and trauma
- Grief, disbelief, and the difficulty of “joining the club”
- Navigating prognostic despair and reclaiming hope
- Role of community connection in restoring meaning and trust
- Clinician role in validating fear while modeling optimism grounded in reality
- Doctors told us what wasn’t possible; the community showed us what was.

1:35 – 1:50 | Psychological Re-orientation & Identity (15 min)

- From disorientation to re-orientation: adapting to “life on a new planet”
- Identity shift for patients, parents, and siblings
- The importance of preserving self beyond the diagnosis
- Encouraging reconnection to joy, purpose, and self-care
- Therapeutic interventions to reduce isolation and foster belonging
- Support clients in exploring who they are outside of rare disease while honoring what has changed.

1:50 – 2:00 | Closing & Q + A (10 min)

- Key takeaways and clinical applications
- How to claim CE credit
- Opportunities to join the Give an Hour Cadre
- Preview of upcoming modules
- Participant Q&A

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

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Jan. 7th
12:30 PM

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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.



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TRAINING AGENDA



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Jan. 7th
12:30 PM

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
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flow and audience needs.**

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March 4th, 2026
12:30 PM

MODULE 3: BARRIERS AND BREAKTHROUGHS: SUPPORTING MENTAL HEALTH IN THE SYSTEMIC RARE JOURNEY



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

Learning Objectives:



Describe how systemic barriers across medical, insurance, and government programs (SSI, SSDI, waivers, school systems) contribute to chronic stress and emotional dysregulation in individuals and families living with rare conditions.



Identify common gaps in medical expertise, communication patterns, and care coordination that lead to frustration and grief for rare patients, and outline strategies clinicians can use to validate and support these experiences.



Apply trauma-informed and collaborative care principles to strengthen partnerships with overwhelmed medical professionals, educators, and service providers who may know less about a rare condition than the patient or caregiver.

Description:

In this module, providers will learn how to support rare disease clients as they navigate complex medical, mental health, insurance, and government systems. Clinicians will explore how limited medical expertise, fragmented services, and overburdened providers contribute to frustration, uncertainty, and emotional fatigue for individuals and families. Using a trauma-informed and collaborative approach, the session offers practical strategies to validate client experiences, and strengthen resilience and hope throughout the systemic rare journey.

INSTRUCTORS:

Dr. Al Freedman

Psychologist, Educator, & Rare Disease Advocate

Kaitlin Maud, LPC Associate

Art Therapist



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.



Speaker bio: Kaitlin Maud, LPC Associate, ATR-P (she/they) is an art therapist, mental health counselor, and facilitator based in Austin, Texas. Her work focuses on supporting individuals navigating complex diagnoses and life transitions. Kaitlin brings experience as both a clinician and researcher, and has facilitated trainings, workshops, and groups for patients, providers, and organizational teams. Her approach emphasizes nuance, accessibility, and relational care- helping people build capacity for attunement with those whose needs are often misunderstood or overlooked. In addition to her professional background, Kaitlin brings lived experience as a rare disease patient, informing her commitment to patient-centered, trauma-informed, and ethically grounded care.

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Originally
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March 4th, 2026
12:30 PM

AGENDA – Module 3: Barriers and Breakthroughs: Supporting Mental Health in the Systemic Rare Journey

Date: March 4th | 12:30 PM ET

Duration: 90 minutes (1.5 CE credits)

Format: Live synchronous distance learning (Non-interactive)

Instructors: Al Freedman, PhD and Kaitlin Maud, LPC

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

- Welcome from Give an Hour and Alexion
- Introduce facilitators (Al Freedman, PhD and Kaitlin Maud, LPC)
- Training overview and CE objectives
- Participant safety and emotional-care reminders

12:40 – 12:55 | Systemic Burden as a Core Clinical Stressor (15 min)

- Identify how ongoing exposure to medical, insurance, disability, educational, and employment systems can contribute to chronic stress and emotional dysregulation in rare disease populations.

12:55 – 1:05 | Recognizing and Validating Rational Distress Without Pathologizing (10 min)

- Recognize emotional and behavioral responses that reflect rational distress in the context of chronic systemic strain and uncertainty.
- Validate lived experience without pathologizing adaptive coping or survival responses.

1:05 – 1:15 | Clinical Logic vs. System Logic (10 min)

- Describe how misalignment between clinical care and system requirements can contribute to frustration, grief, and erosion of trust.
- Define the role of mental health treatment when systemic barriers persist and external change is limited.
- Use validation strategies that acknowledge system mismatch without attempting to rationalize or defend system behavior.

1:15 – 1:25 | Repetition Burden and Capacity Depletion (10 min)

- Identify the cognitive and emotional toll of repeated retelling, documentation, archiving, researching, education, and advocacy within systems on patients and caregivers.
- Implement practical strategies to reduce advocacy fatigue and preserve client capacity.

1:25 – 1:35 | VI. Work, Income, and Economic Stability as Clinical Domains (10 min)

- Examine how employment instability, income insecurity, and access to accommodations affect mental health in rare disease contexts.
- Support clients in making autonomous decisions around disclosure, accommodations, and planning for fluctuating capacity

1:35 – 1:45 | Educational Systems as Parallel Sites of Harm or Safety (10 min)

- Describe how educational processes, including IEPs and 504 plans, can function as sources of stress and/or support for children and families.
- Apply trauma-informed approaches to support families navigating education systems.

1:45 – 1:55 | Timing and Transitions Across Systems (10 min)

- Identify system transition points (diagnosis, insurance changes, school transitions, employment changes) as periods of heightened psychological vulnerability.
- Anticipate and address emotional, relational, and identity-related impacts associated with system transitions.

1:55 – 2:00 | Closing (5 min)

- Define the role of mental health treatment when systemic barriers persist and external change is limited.
- Practice role-appropriate interventions grounded in steadiness, ethical hope, and respect for client autonomy.

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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



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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.

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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

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Originally
Recorded:

JULY 1st
12:30 ET



MODULE 5: POWER OF BELONGING: PEER AND ADVOCACY SUPPORT IN RARE MENTAL HEALTH

Description:

Living with a rare disease can be profoundly isolating for both individuals and families. While medical care addresses important clinical needs, connection with others who share similar experiences often provides a unique source of understanding, validation, hope, and belonging. This module explores the role of peer support, advocacy organizations, and community networks in reducing isolation and supporting well-being across the rare disease journey.

Participants will examine the core elements of effective peer support, including shared lived experience, mutual validation, community-building, and identity development. The module will also explore how engagement in support and advocacy communities can influence coping, resilience, meaning-making, and long-term adjustment. Clinicians will gain practical strategies for helping clients identify, access, and engage with supportive communities while recognizing the unique benefits and limitations of peer-based support.

INSTRUCTORS:

Dr. Al Freedman

Psychologist, Educator, & Rare Disease Advocate

Dr. Kathleen Bogart

Professor of Psychology Oregon State University



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.



Kathleen Bogart, Ph.D., is a Professor of Psychology at Oregon State University. She earned her Ph.D. in experimental social psychology from Tufts University in 2012. As a person with a disability, she is passionate about researching, educating, and writing about ableism, or disability prejudice. Her research focuses on the psychosocial implications of living with disability, rare disorders, or facial differences such as Moebius syndrome. An advocate for people with disabilities, she has served on the American Psychological Association Committee on Disability Issues in Psychology, the Rehabilitation Psychology editorial board, and the Moebius Syndrome Foundation Scientific Advisory Board.



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

Learning Objectives:



Identify the role of peer support and advocacy communities in reducing isolation and supporting psychosocial well-being among persons living with rare disease and their families.



Describe key elements of effective peer support in rare disease contexts, including shared lived experience, validation, and community connection.



Explain how engagement in peer and advocacy networks influences coping, identity, and sense of belonging in persons living with rare disease.

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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.
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- 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.

BEYOND THE DIAGNOSIS

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

TRAINING AGENDA

FREE Virtual LIVE Training Hosted by Give an Hour, and Supported by Alexion



Originally
Recorded on
Wednesday
July 1st, 12:30 ET

BEYOND THE DIAGNOSIS

TRAINING AGENDA

Module 5: The Power of Belonging: Peer Support, Advocacy, and Community in Rare Disease

Date: Wednesday, July 1st 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 & Kathleen Bogart, PhD

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 and social isolation
- The role of belonging and validation
- Importance of peer and advocacy support

12:40 – 1:00 | Understanding Isolation and Connection in Rare Disease (20 min)

Social Isolation & Emotional Disconnection

- Feeling misunderstood or unseen
- Identity disruption and loss of normalcy

Trauma, Grief, & Belonging

- Community shows us what's possible
- The role of connection in reducing isolation
- Belonging and validation in rare disease communities

1:00 – 1:25 | Peer Support & Advocacy in Rare Disease Communities (25 min)

Peer Support in Rare Disease

- Validation through lived experience
- Different types of peer spaces and support models
- Clinician-led and community-led peer support spaces

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

Advocacy & Identity Reconstruction

- Finding meaning and purpose through advocacy
- Rebuilding identity and agency
- Community as a source of hope and resilience

1:25 – 1:50 | Clinical Applications for Supporting Connection & Belonging (25 min)

- Trauma-Informed Clinical Support
- Creating emotionally safe therapeutic spaces
- Supporting persons living with rare disease and caregivers
- Supporting Sustainable Connection
- Encouraging meaningful social support
- Helping clients reconnect with joy and identity
- Recognizing caregiver and sibling experiences

1:50 – 2:00 | Closing Reflections & Key Takeaways (10 min)

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

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



Wednesday,
September 2nd, 2026
12:30 ET

MODULE 6: BRIDGING GAPS IN CARE: RARE DISEASE MENTAL HEALTH STRATEGIES



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

Description:

Living with a rare disease requires more than symptom management. It calls for care that recognizes the whole person, values lived expertise, and extends beyond the clinical encounter. This module equips clinicians with practical strategies to deliver patient-centered care, collaborate effectively across the broader care ecosystem, and support individuals and families navigating the ongoing psychosocial challenges of rare disease. Participants will explore approaches that strengthen therapeutic partnerships, foster resilience and self-advocacy, and bridge gaps between healthcare, mental health, and community-based support systems to improve continuity of care.

INSTRUCTORS:

Dr. Al Freedman

Psychologist, Educator, & Rare Disease Advocate

Laura Govendo, LCPC

Rare Disease Consultant, and Advocate

Learning Objectives:



Apply patient-centered communication and care strategies that validate lived experience, address uncertainty, and strengthen therapeutic partnerships with individuals living with rare diseases.



Integrate systems-level approaches that enhance collaboration with caregivers, interdisciplinary care teams, advocacy organizations, and community resources to improve coordination and continuity of care.



Implement practical and clinical strategies that strengthen patient resilience, promote self-advocacy, and support long-term psychosocial well-being throughout the rare disease journey.



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.



Lara Govendo, LCPC, is a licensed clinical professional counselor, consultant, and rare disease advocate. Drawing on both her professional expertise and lived experience with cystic fibrosis and a double-lung transplant, Lara specializes in helping individuals, families, healthcare organizations, and rare disease communities navigate the psychosocial challenges of complex medical conditions. Through her consulting, speaking, and clinical work, she promotes patient-centered care, resilience, and practical strategies that strengthen mental health and collaboration across the rare disease ecosystem.

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TRAINING AGENDA

FREE Virtual LIVE Training Hosted by Give an Hour, and Supported by Alexion



Wednesday
September 2nd, 2026
12:30 ET

BEYOND THE DIAGNOSIS

TRAINING AGENDA

Module 6: Bridging Gaps in Care: Rare Disease Mental Health Strategies

Date: Wednesday, September 2nd 12:30 PM – 2:00 PM ET

Duration: 90 minutes (1.5 CE credits)

Format: Live synchronous distance learning (non-interactive)

Instructors: Al Freedman, Lara Govendo LCPC

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

- Overview of module objectives
- The evolving role of mental health clinicians in rare disease care
- From individual treatment to systems-informed practice

12:40–1:00 | Patient-Centered Care Beyond the Diagnosis (20 min)

Listening Before Leading

- Avoiding assumptions and diagnostic overshadowing
- Validating lived experience while recognizing co-occurring mental health needs
- Navigating uncertainty with flexibility and curiosity

Building Therapeutic Partnerships

- Meeting patients where they are
- Strengthening trust through patient-centered communication
- Adapting the therapeutic approach to evolving patient needs

1:00–1:25 | Strengthening the Rare Disease Care Ecosystem (25 min)

Systems-Level Collaboration

- Working effectively with caregivers and families
- Collaborating across interdisciplinary care teams
- Understanding the role of advocacy organizations and community resources
- Supporting healthcare navigation and self-advocacy

Facilitating Connection & Empowerment

- Helping patients build a sustainable network of care
- Assessing readiness for support

1:25–1:50 | Practical Strategies for Long-Term Well-Being (25 min)

Flexible, Responsive Clinical Practice

- Balancing therapeutic interventions with real-world problem solving
- Supporting patients through changing medical and psychosocial challenges
- Knowing when listening is the intervention

Promoting Resilience Across the Rare Disease Journey

- Building confidence and self-efficacy
- Supporting long-term adaptation and identity reconstruction
- Practical strategies clinicians can implement immediately

1:50–2:00 | Closing Reflections & Key Takeaways (10 min)

- Key practice recommendations
- Applying patient-centered and systems-informed approaches
- Final questions and reflections
- CE credit instructions
- Closing remarks

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

1.5 HOUR CE Credit (See Page 2)

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Psychologist, Educator, & Rare Disease Advocate

Laura Govendo, LCPC

Rare Disease Consultant, and Advocate

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