Recorded Asynchronous Hosted on Zoom

# BEYOND THE DIAGNOSIS

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

**1.5 HOUR CE Credit Approved**

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

**Originally recorded on Nov. 12th 12:30 PM**

## 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**

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# COURSE COMPLETION AND CE INFORMATION

## FOR GIVE AN HOUR MENTAL HEALTH PROFESSIONAL LIVE TRAINING & WORKSHOPS

### Course completion requirements:

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Recorded Asynchronous Distance Course

# BEYOND THE DIAGNOSIS

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

## 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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**1.5 HOUR CE Credit Approved (See Page 2)**

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

**Originally recorded on Jan. 7th 12:30 PM**

## 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



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*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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# BEYOND THE DIAGNOSIS

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

## TRAINING AGENDA

Originally recorded on 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 adjustments based on presenter flow and audience needs.**

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**1.5 HOUR CE Credit (See Page 2)**

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

**Originally Recorded on 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**

### 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.

### 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.

### INSTRUCTORS:

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

**Kaitlin Maud, LPC Associate**
Art Therapist



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*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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## TRAINING AGENDA

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

Originally Recorded on 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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**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

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

### 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.

### 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.**

### 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.*


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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

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# 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: 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

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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*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.*

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# 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

**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

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# 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 on Wednesday, September 2nd 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.

### 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.**

### INSTRUCTORS:

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

**Laura Govendo, LCPC**
Rare Disease Consultant, and Advocate



*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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# 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 September 2nd, 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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# 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 on Wednesday, October 7th 2026 12: 30 ET**

## MODULE 7: PASSING THE TORCH: SUPPORTING RARE PATIENTS ACROSS LIFE STAGES

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

### Description:

For people living with rare disease and their families, transitions are rarely simple handoffs. Changes in education, healthcare, independence, family roles, and support systems can introduce new uncertainty, loss, and gaps in care. From receiving a diagnosis and navigating school-based services to transitioning from pediatric to adult healthcare, developing greater autonomy, and coping with bereavement and loss, each life stage may require patients and families to continually adapt.
This module explores the unique emotional, relational, and systemic challenges that can accompany transitions across the rare disease journey. Mental health professionals will learn how to recognize transition-related stress, support evolving patient and caregiver roles, and help individuals and families navigate change while maintaining continuity, autonomy, and connection.

### INSTRUCTORS:


**Al. Freedman, PhD**
Psychologist, Educator, & Rare Disease Advocate

**Jennifer Caughlin, PhD**
Psychologist, President, Caughlin Research


### Learning Objectives:

- **Identify key transition points across the rare disease lifespan and describe how medical complexity, fragmented systems, changing services, and uncertainty can intensify their emotional and practical impact.**
- **Recognize the evolving needs of patients and caregivers during transitions, including changes in identity, autonomy, family roles, caregiving responsibilities, and readiness for greater independence.**
- **Apply practical, developmentally appropriate strategies to support patients and families through transitions, including anticipatory preparation, incremental transfer of responsibility, continuity of support, and navigation of grief and loss.**



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*Jennifer Caughlin, PhD, is a licensed psychologist and President & CEO of Caughlin Research, where she specializes in qualitative research designed to better understand the experiences, needs, and perspectives of patients and communities. With more than 30 years of research experience, her work has included extensive collaboration with rare disease communities, using patient-centered research to illuminate lived experiences and unmet needs. She has also contributed to the development of rare disease patient registries and research examining the natural history and impact of rare conditions.*


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# 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, October 7th 2026

**TRAINING AGENDA**
**Module 7: Passing the Torch: Supporting Rare Patients Across Life Stages**
**Date:** Wednesday, October 7, 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, and Jennifer Caughlin, PhD

**12:30–12:40 | Welcome & Training Overview (10 min)**
**Understanding Transition Across the Rare Disease Lifespan**

- Overview of module objectives
- Transition as a universal human experience complicated by rare disease
- The interaction of lifespan development, disease progression, and systems change
- Predictable versus unexpected transitions
- Introducing the concept of "Passing the Torch": how care, responsibility, support, and identity shift over time

**12:40–1:00 | Transitions Within Transitions: What Rare Disease Adds (20 min)**
**Navigating Developmental, Medical & System Change**

- Developmental milestones across childhood, adolescence, adulthood, and aging
- School, healthcare, insurance, caregiving, and service-system transitions
- Disease progression and loss of function as an ongoing transition
- Hospitalization and returning home as major disruptions
- How one transition can create cascading changes across multiple areas of life
- Why chronological age may not reflect developmental readiness
- ***Clinical Vignette: A Familiar Transition, Made More Complex***

**1:00–1:25 | Passing the Torch: Autonomy, Caregiving & Changing Roles (25 min)**
**Supporting Developmentally Appropriate Independence**

- Supporting evolving identity, autonomy, and self-advocacy
- Gradually transferring responsibility for appointments, medications, communication, and care
- Matching responsibility to developmental capacity and task complexity
- Supporting caregivers as their role shifts from managing care to sharing or relinquishing responsibility
- Preparing for the Transition Before It Happens
- Clinical Vignette: Case Example

**1:25–1:50 | Holding Continuity Through Change, Grief & Loss (25 min)**
Navigating Loss & Uncertainty

- Loss of function, independence, roles, services, and familiar supports
- Ambiguous and anticipatory grief across the rare disease journey
- Aging, caregiver transitions, bereavement, and changing family roles
- The Clinician as a Source of Continuity: Providing stability while systems and circumstances change
- Maintaining continuity of care, trust, and support across transitions

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

- Recognizing the added complexity rare disease brings to familiar life transitions
- Providing continuity when other parts of the patient's world are changing
- CE credit instructions and closing remarks

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

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# 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, November 4th 2026**
**12: 30 ET**

## MODULE 8: FROM BREAKTHROUGHS TO BURDENS: WHEN SCIENCE BRINGS HOPE AND COMPLEXITY

### Description:

Scientific advances are transforming what is possible for people living with rare diseases, bringing new treatments, technologies, and reasons for hope. Yet progress can also introduce new sources of uncertainty and emotional strain. Patients and families may face difficult decisions about emerging therapies, questions of access and affordability, unclear long-term outcomes, and the pressure to remain hopeful when a promising option may not be available, appropriate, or effective for them.
This module explores the psychological and relational impact of scientific progress in rare disease care. Participants will examine how clinicians can acknowledge both hope and burden, support patients and families navigating complex treatment decisions, and communicate about emerging possibilities without minimizing uncertainty, grief, or the realities of living with rare disease.

### INSTRUCTORS:


**Al. Freedman, PhD**
Psychologist, Educator, & Rare Disease Advocate

**Nancy Cincotta, LCSW, MPhil, MSW, OSW-C**
Chief Psychosocial Officer - Richi Childhood Cancer Foundation, Psychosocial Consultant, Narrative Medicine Practitioner


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

### Learning Objectives:

- **Identify at least three psychological or relational stressors associated with emerging treatments and scientific advances in rare disease care, including uncertainty, access barriers, and changing expectations.**
- Differentiate between communication approaches that support realistic hope and those that may unintentionally reinforce pressure, false certainty, or emotional invalidation when discussing emerging treatment options.
- Describe at least two patient-centered strategies for supporting individuals and families as they navigate treatment decisions, uncertainty, and the emotional complexity associated with scientific progress.



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*Nancy Cincotta, LCSW, MPhil, is OCRA's Senior Director of Social Work Education and Research (Consultant) and a Psychosocial Consultant for 15 oncology programs nationwide. Ms. Cincotta has worked in non-profit, hospital, and higher education settings throughout her 40+ years in Oncology Social Work. She has extensive expertise working with children with life-threatening illnesses and their families. She has worked with bereaved parents and children in individual and family work, in groups, and in a retreat format. Ms. Cincotta is widely published in this area and has presented extensively on national and international levels.*


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

Live synchronous distance learning (non-interactive)

# 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*

**Wednesday, November 4th 2026**

**Module 8: From Breakthroughs to Burdens: When Science Brings Hope and Complexity**
**Facilitators:** Al Freedman, PhD and Nancy Cincotta, LCSW, MPhil, MSW, OSW-C
**Duration: 90 minutes**
**Format:** Live synchronous distance learning, non-interactive
CE Credits: 1.5 CE credits

**12:30–12:40 | Welcome & Training Overview (10 min)**
When Science Changes the Rare Disease Story

- Overview of module objectives
- The rare disease treatment landscape: scientific progress within the context of limited disease-specific treatment options
- Introducing the central tension: progress can create hope without eliminating uncertainty

**12:40–1:00 | The Emotional Complexity of Scientific Progress (20 min)**
Hope, Uncertainty & the Changing Future

- Uncertainty as a persistent psychological burden before, during, and after scientific progress
- Anticipatory anxiety: waiting for science to "catch up"
- Decision burden and fear of making the "wrong" choice when evidence is still emerging
- Grief when a promising trial fails or development is discontinued

**1:00–1:20 | When a Breakthrough Isn't Equally Available (20 min)**
**Access, Eligibility & the Haves and Have-Nots**

- Barriers to access: eligibility criteria, geography, cost, insurance, and treatment availability
- Clinical trial complexities: limited enrollment, randomization/placebo, expanded access, and uncertainty of benefit
- Ethical and emotional impacts when potentially life-changing treatments are available to some but not others
- Community impacts of unequal access, including survivor guilt, grief, anger, and feelings of unfairness or exclusion

**1:20–1:40 | When Treatment Changes More Than the Disease (20 min)**
Identity, Relationships & the Unexpected Consequences of Getting Better

- Identity shifts when treatment changes a long-established disease trajectory, future expectations, or sense of self
- Disability identity and respecting different relationships to treatment, including decisions not to pursue available options
- Changes in patient, caregiver, partner, and family roles following successful treatment
- Survivor guilt, belonging, and changing relationships within rare disease communities
- Recognizing that psychological needs may persist or emerge after treatment, without assumptions about what improvement or cure "should" mean

**1:40–1:55 | Supporting Realistic Hope & Patient-Centered Decision Making (15 min)Holding Hope Without Promising an Outcome**

- Making space for hope, fear, grief, skepticism, and ambivalence without pressure to "stay positive"
- Supporting informed decisions without steering patients toward or away from treatment
- Centering patient values, identity, priorities, and individual definitions of quality of life
- Recognizing imperfect choices and respecting decisions not to pursue available treatment
- Helping patients remain grounded in the present while holding space for future possibilities
- Clinical application: Using language that validates uncertainty while preserving realistic hope

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

- cientific progress can reduce uncertainty while creating new emotional and practical challenges
- Treatment availability does not guarantee access, effectiveness, certainty, or emotional resolution
- Hope and grief can coexist throughout the treatment journey
- Patient-centered support centers listening, values, and navigating uncertainty without imposing an outcome
- CE credit instructions and closing remarks

**Contact Info for Questions or Grievances**
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