Mental Health. For Life.

MENTAL HEALTH PROFESSIONAL

BEYOND THE DIAGNOSIS TRAINING SERIES

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ABOUT GIVE AN HOUR

Give an Hour® is a nonprofit organization dedicated to transforming mental health care through innovation, collaboration, and community-centered approaches. We develop accessible, barrier-free programs that empower individuals to take charge of their emotional well-being while supporting those who serve them—including mental health professionals, peer supporters, and community partners.

Our mission is to develop resilient individuals and their communities, grow our social impact through responsive, scalable, and individualized mental health programs, and close mental health support access and delivery gaps.

EQUIPPING CLINICIANS TO NAVIGATE THE PSYCHOLOGICAL TOLL OF RARE DISEASE

Beyond the Diagnosis: Emotional, Social, and Systemic Challenges within the Rare Disease Community explores the complex journey of individuals, caregivers, and families affected by rare diseases. This training series provides mental health professionals with insights into the nuanced emotional, social, and systemic challenges that arise from a rare disease diagnosis or lack thereof. Participants will learn about the psychological impact within the rare world, coping with uncertainty, navigating healthcare and support systems, the effects on family and social relationships, the importance of community and peer support, mental health challenges, transitional complexities, and the implications of emerging treatments. Through case examples, evidence-informed strategies, and practical guidance, this series equips providers to better support people with the diagnosis, caregivers, and families through the continuum of care, fostering resilience, trauma informed decision-making, and holistic care.

BRIDGING THE GAP IN MENTAL HEALTH CARE

Through trauma-informed, survivor-centered modules, mental health professionals will learn to:

- Identify emotional, cultural, and lived-experience factors shaping mental health needs in the rare disease community.
- Apply evidence-based strategies to clinical case examples to strengthen treatment planning, therapeutic communication, and sensitivity in working with the rare disease community.
- Integrate subject matter expertise, peer insights, and evidence-based resources to sustain rare disease–informed practices in ongoing clinical work.
- Identify the key sources of information and support (including advocacy groups, pharmaceutical companies, researchers, and institutions) that members of the rare disease community rely on.

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Dear Esteemed Providers,

Welcome to ***Beyond the Diagnosis: Emotional, Social, and Systemic Challenges Within the Rare Disease Community***—an eight-part, CE-accredited training series developed by Give an Hour in collaboration with leading experts and lived-experience voices in the rare disease space.

This training series was designed to deepen understanding of the complex emotional, social, and systemic realities faced by individuals and families living with a rare condition. A rare disease diagnosis—or the long, uncertain road to one—is not just a medical experience; it's a profound psychological and relational event that reshapes identity, trust, and hope.

Through this groundbreaking series, you'll explore the nuanced intersections of trauma, uncertainty, and resilience that define the rare disease journey. Each module invites reflection on key dimensions of the rare experience: the diagnostic odyssey, systemic barriers, caregiver strain, peer and family dynamics, the power of community belonging, and the emotional complexities that accompany both medical breakthroughs and ongoing loss.

At Give an Hour, we believe mental health professionals are uniquely positioned to bring healing and stability to the rare disease community—yet many have not had access to the insights or language needed to do so. ***Beyond the Diagnosis*** bridges that gap by equipping providers with trauma-informed, rare-informed, and family-centered strategies for care.

By completing this series, you join a growing network of clinicians committed to inclusive, compassionate, and evidence-informed care—helping individuals and families living with rare conditions rebuild trust, connection, and meaning beyond the medical chart.
Thank you for your dedication to this vital work and for standing with us in expanding access to mental health care that truly sees the whole person behind the diagnosis.

Trina Clayeux

Dr. Trina Clayeux
CEO, Give an Hour

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Dear Mental Health Professional,

Welcome to Give an Hour. Your expertise, compassion, and commitment have the power to change lives, and we're honored to welcome you. As a licensed mental health professional, you have the opportunity to join a nationwide network of providers offering vital, barrier-free support to individuals who might otherwise go without care.

At Give an Hour, our mission is to build a community of 50,000 strong, mental health professionals dedicated to healing, hope, and service. We're thrilled to invite you to be part of this powerful movement.

Inside this welcome packet, you'll find everything you need to get started with ***Beyond the Diagnosis: Emotional, Social, and Systemic Challenges Within the Rare Disease Community***, our specialized training series focused on the emotional and psychological impact of navigating the mental health challenges of rare disease. You'll also learn more about Give an Hour's ongoing commitment to supporting our network of volunteer providers.

If you're new to our community—welcome! This packet highlights the many benefits of joining our provider network, including professional development opportunities, cultural competence trainings, and meaningful connections with fellow clinicians who share your passion for giving back.

We're here to support you—every step of the way.

Together, we can transform lives, one hour at a time.

Warmly,

Julie Wells

Julie Wells
Director of Strategic Relationships
Give an Hour

"We're so grateful to have you join our community. Your time, expertise, and heart make all the difference."

BEYOND THE DIAGNOSIS

Emotional, Social, and Systemic Challenges Within the Rare Disease Community

Hosted by Give an Hour, and Supported by Alexion

REGISTER

12 HOUR CE Credit, NBCC | ASWB | APA

12:30pm EST

Nov. 12, 2025	Module 1: The First Step: Trauma, Trust, and Re-Orienting to Life with Rare
Jan. 7. 2026	Module 2: Between Answers & Ambiguity: Coping with the Unknown in Rare
Mar. 4, 2026	Module 3: Barriers and Breakthroughs: Supporting Mental Health in the Systemic Rare Journey
May. 6, 2026	Module 4: Isolation to Connection: Understanding Relationship Strain in Rare
Jul. 1, 2026	Module 5: Power of Belonging: Peer and Advocacy Support in Rare Mental Health
Sep. 2, 2026	Module 6: Bridging Gaps in Care: Rare Disease Mental Health Strategies
Oct. 7, 2026	Module 7: Passing the Torch: Supporting Rare Patients Across Life Stages
Nov. 4, 2026	Module 8: From Breakthroughs to Burdens: When Science Brings Hope and Complexity

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

1.5 CREDIT HOURS

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.

Mental health providers will gain insight into how the diagnostic process itself can create trauma, from delays and misdiagnoses to the challenges of entering a world with limited resources and support. Participants will learn to recognize the distinct mental health needs of people with the diagnosis, caregivers, and families at various stages, including the newly diagnosed, those managing ongoing care, and those navigating loss.

Through this training, providers will build the knowledge and skills necessary to support the rare disease community with sensitivity, clinical insight, and trauma-informed care.

Module 1 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.

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

1.5 CREDIT HOURS

Uncertainty is an inescapable part of the rare disease experience, whether waiting months or years for a diagnosis, navigating unpredictable symptoms, or facing existential questions about meaning, mortality, and identity. For many individuals and families, “living between answers” becomes a chronic state that challenges their sense of control, safety, and hope.

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.

Module 2 Learning Objectives:

- Describe the pervasive role of uncertainty in the rare disease experience, from macro-level existential questions (“Why me?” “What does this mean for my family?”) to micro, day-to-day concerns about care, access, and stability.
- Identify common psychological and physiological responses to prolonged uncertainty, including anxiety, hyper-vigilance, and loss of perceived control, 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.
- Apply trauma-informed, resilience-building, and meaning-making approaches to help clients, and clinicians themselves, tolerate ambiguity, sustain agency, and preserve well-being when outcomes remain unknown.
- Examine the ethical, emotional, and relational dynamics surrounding clinical-trial participation, including clients’ tolerance for risk, hope for breakthroughs, and navigation of uncertain outcomes.

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

1.5 CREDIT HOURS

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, partner effectively with multidisciplinary teams, and strengthen resilience and hope throughout the systemic rare journey.

Module 3 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.

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

1.5 CREDIT HOURS

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.

Module 4 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.

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

1.5 CREDIT HOURS

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.

Module 5 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.

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

1.5 CREDIT HOURS

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

1.5 CREDIT HOURS

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

1.5 CREDIT HOURS

MEET YOUR FACILITATORS

MODULE 1 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.

MODULE 2 INSTRUCTORS:

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

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

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.

MEET YOUR FACILITATORS

MODULE 3 INSTRUCTORS:

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

Kaitlin Maud, LPC Associate
Art Therapist

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.

MODULE 4 INSTRUCTORS:

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

Rhonda Thorington, LPC
Chronic Illness - Parent Coach

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.

MEET YOUR FACILITATORS

MODULE 5 INSTRUCTORS:

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

Dr. Kathleen Bogart
Professor of Psychology Oregon State University

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.

BEYOND THE DIAGNOSIS

Become Part of Our National Cadre of Experts

WHY JOIN?

01 FREE CE'S

Specialized training in rare disease trauma (CEUs provided)

02 MENTORSHIP

National mentorship program for early-career MHPs

03 TRAUMA-INFORMED CARE

Contribute to shaping new trauma-informed standards of care

04 JOIN THE MOVEMENT

Become part of a growing professional movement focused on fraud-related trauma

> ***"Click the button on the website and join! It's one of the most rewarding ways to use your clinical skills to make a real impact."***
>
> – Dr. Jennifer Lawrence, GAH Provider

JOIN AN ELITE NETWORK OF MENTAL HEALTH PROVIDERS

Give an Hour invites you to join our Cadre of Provider Experts—a learning community focused on developing clinical expertise in addressing the trauma of rare disease. These meetings will take place on ***the second Wednesday of each month***, following the training webinars held on the first Wednesday of the month. While the webinars will provide clinical insights and foundational knowledge on that month's topic, the Cadre Meetings are designed to deepen your learning and connection.

During each Cadre Meeting, you'll have the opportunity to:

- Reflect on the training content and how it applies to your practice
- Ask in-depth questions and engage in further discussion with trainers and guest speakers
- Access additional resources and tools to support your clinical work
- Connect and network with other providers in a supportive environment
- Combat isolation by learning alongside a community of peers equally committed to understanding rare diseases and their impact

We hope these meetings offer a safe, empowering space for dialogue, support, and professional growth.

Give an Hour | Alexion
Supporting the Rare Disease Community
www.giveanhour

Click. Sign Up.
Change Lives.

The Give an Hour Commitment

The Give an Hour general commitment is that all providers are expected to see at least one client pro bono for an hour once a week for up to a year. We understand that not all clients may need services this frequently, so the timeframes are flexible. This means it is entirely up to you and the client to decide how frequently you meet. However, seeing at least one client pro bono is required since it aligns with our mission of providing access to care to those in need. In return, Give an Hour provides numerous benefits, including professional development, CEU opportunities, and networking resources. **Sign-Up Today**

> According to the National Institute of Mental Health (NIMH), in 2022, approximately 59 million adults in the United States—representing about 23% of the adult population—experienced some form of mental health struggles within the past year.

Benefits of Volunteering With Give an Hour

Professional Development

Unlock growth opportunities, including continuing education units (CEUs) in areas such as military mental health, self-care, and advanced care techniques.

Self-Care for Clinicians:

Learn strategies to care for your own mental health while supporting others. Introduce information of self-care like a Help the Helpers tool.

Flexible Client Load

You control your availability and client load, allowing you to balance your private practice with your desire to give back.

Access Exclusive Resources

From mental health tools to the latest research, Give an Hour provides all the resources you need to stay ahead of the curve in mental health practice.

ON-DEMAND

EMPOWERING MENTAL HEALTH PROVIDERS

UNVEILING THE YEAR OF THE PROVIDER PROGRAM AND BEYOND

Recorded: Jan 26, 2024, 11:54 AM Eastern Time

Join us for an insightful journey into Give an Hour's latest initiatives, including the much-anticipated YEAR OF THE PROVIDER program. This event will provide a comprehensive overview of our plans and purpose for the upcoming year, and we can't wait for you to be a part of it.
Here's a glimpse of what awaits you during this special occasion:

Give an Hour - Supporting Providers Across the Nation

Registration Link

DESCRIPTION OF THE EVENT

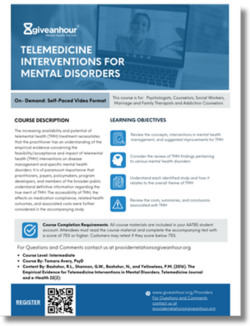
Understanding YEAR OF THE PROVIDER: Gain profound insights into what this groundbreaking program means for you.

Engage with Leadership: Connect with our CEO and leadership team, discovering the impactful numbers and milestones achieved by Give an Hour.

Explore Community Support: Dive into the extensive support that Give an Hour provides for you and our community.

As a gesture of our gratitude, special prizes await those who register and attend. This is your opportunity to become an integral part of our vibrant community and stay at the forefront of the exciting initiatives we have in store for the YEAR OF THE PROVIDER!

Stay tuned for more details, and we look forward to having you with us on these significant dates.



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TELEMEDICINE INTERVENTIONS FOR MENTAL DISORDERS

On- Demand: Self-Paced Video Format

This course is for: Psychologists, Counselors, Social Workers, Marriage and Family Therapists and Addiction Counselors

COURSE DESCRIPTION

The increasing availability and potential of telemental health (TMH) treatment necessitates that the practitioner has an understanding of the empirical evidence concerning the feasibility/acceptance and impact of telemental health (TMH) interventions on disease management and specific mental health disorders. It is of paramount importance that practitioners, payers, policymakers, program developers, and members of the broader public understand definitive information regarding the true merit of TMH. The accessibility of TMH, the effects on medication compliance, related health outcomes, and associated costs were further considered in the accompanying study.

LEARNING OBJECTIVES

Review the concepts, interventions in mental health management, and suggested improvements for TMH

Consider the review of TMH findings pertaining to various mental health disorders

Understand each identified study and how it relates to the overall theme of TMH

Review the costs, summaries, and conclusions associated with TMH

Course Completion Requirements: All course materials are included in your AATBS student account. Attendees must read the course material and complete the accompanying test with a score of 75% or higher. Customers may retest if they score below 75%.

For Questions and Comments contact us at providerrelations@giveanhour.org

- **Course Level: Intermediate**
- **Course By: Tamara Avery, PsyD**
- **Content By: Bashshur, R.L., Shannon, G.W., Bashshur, N., and Yellowlees, P.M. (2016). The Empirical Evidence for Telemedicine Interventions in Mental Disorders. Telemedicine Journal and e-Health 22(2):**

REGISTER

www.giveanhour.org/Providers
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Peer Support and Networking

Join a supportive network of mental health professionals and expand your practice through meaningful connections and collaborative opportunities.

Cultural Competence

By working with diverse populations, you will gain valuable experience that enhances your cultural understanding and competence in the field.

Mentorship Opportunity

Early career professionals can access mentorship opportunities as they work toward full licensure.

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