

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.

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.

Contact Info for Questions or Grievances

<https://giveanhour.org> | Give an Hour, PO Box 1532,
Clarksburg, MD 20871 | 240-745-5641
providerrelations@giveanhour.org

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COURSE COMPLETION AND CE INFORMATION

FOR GIVE AN HOUR MENTAL HEALTH PROFESSIONAL LIVE TRAINING & WORKSHOPS

Course completion requirements:

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

CE Statements:

- Give an Hour provider # 2097, is approved as an ACE provider to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Regulatory boards are the final authority on courses accepted for continuing education credit. ACE provider approval period: 04/30/2025– 04/30/2029. 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.

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TRAINING AGENDA

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



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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

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

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