On-Demand Synchronous Distance Course

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.**

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.

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– 04/30/2026. 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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Recorded Asynchronous Hosted on Zoom

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

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

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