

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,
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.



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.



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.

Contact Info for Questions or Grievances

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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.

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TRAINING AGENDA

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



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.