On Demand Asynchronous 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 on 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.



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.



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.

Contact Info for Questions or Grievances
https://giveanhour.org | Give an Hour, PO Box 1532, Clarksburg, MD 20871 | 240-745-5641
providerrelations@giveanhour.org

REGISTER HERE

giveanhour® Mental Health. For Life.

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.

giveanhour®
Mental Health. For Life.

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

Recorded Asynchronous Hosted on Zoom

BEYOND THE DIAGNOSIS

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

TRAINING AGENDA

FREE On-Demand Training Hosted by Give an Hour, and Supported by Alexion

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

REGISTER HERE

giveanhour® Mental Health. For Life.