

# Albert Freedman, Ph.D.

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## EDUCATION

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<b>Ph.D.</b> Counseling Psychology University of Wisconsin-Madison, Madison, WI	May 1996
<b>Ed.M.</b> Counseling Psychology Boston University, Boston, MA	May 1992
<b>Ed.M.</b> Teaching and Curriculum Harvard Graduate School of Education, Cambridge, MA	May 1987
<b>B.A.</b> Sociology University of Pennsylvania, Philadelphia, PA	May 1982

## PROFESSIONAL LICENSES

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<b>Licensed Psychologist, Illinois</b>	2023
<b>Authority to Practice Interjurisdictional Telepsychology PSYPACT Commission</b>	2021
<b>Registered, National Register of Health Service Providers in Psychology</b>	2001
<b>Licensed Psychologist, Pennsylvania</b>	1998
<b>Licensed Professional Counselor, Wisconsin</b>	1995

## PROFESSIONAL EXPERIENCE AND TRAINING

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<b>Freedman Counseling Associates, Haverford, PA</b> Child, Adolescent, Adult, & Family Psychologist	1999-Present
<b>AMF Consulting/Rare Counseling</b> Health Care, Education, and Rare Disease Consultant	2004-Present
<b>Bayada Home Health Care, Moorestown, NJ</b> Consulting Psychologist	2002-2015
<b>Westtown School, Westtown, PA</b> Consulting Psychologist, Lower School Counseling Psychologist, Upper School 3rd Grade Teacher	2006-2014 1996-2002 1983-1986
<b>Delaware Valley Friends School, Paoli, PA</b> Consulting Psychologist	2002-2013
<b>Astor Home for Children, Rhinebeck, NY</b> Doctoral Psychology Intern	1995-1996

<b>Mendota Mental Health Institute</b> , Madison, WI Psychology Trainee, Adolescent Unit	1993-1995
<b>Family Therapy Center of Madison</b> , Madison, WI Psychology Trainee	1993-1995
<b>University of Wisconsin-Madison</b> , Madison, WI Project Director & Course Instructor	1992-1995
<b>Work/Family Directions</b> , Boston, MA Educational Consultant	1990-1994
<b>Wilmington Friends School</b> , Wilmington, DE 2 <sup>nd</sup> /3 <sup>rd</sup> Grade Teacher	1987-1990
<b>University of New Hampshire</b> , Durham, NH Adjunct Faculty, School of Education	1987-1988

## **HONORS AND FELLOWSHIPS**

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**Ray Strowig Memorial Award for Excellence in Teaching and Service**,  
Department of Counseling Psychology, University of Wisconsin-Madison (1994)

**Graduate Fellowship**, Dept. of Counseling Psychology, Boston University (1991-1992)

## **COMMUNITY INVOLVEMENT**

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CureSMA National Medical Advisory Board	2008-Present
Pennsylvania Health Law Project, Health Care Advisory Board	2014-2016
Inglis Foundation, ACE Awards Committee	2012-2016
Family Advisory Council, DuPont Hospital for Children, Founding Member	2006-2015

## **PUBLICATIONS**

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Kenny T, Bogart K, Freedman A, Garthwaite C, Henley SMD, BolzJohnson M, Mohammed S, Walton J, Winter K, & Woodman D. (2022). The importance of psychological support for parents and caregivers of children with a rare disease at diagnosis. *Rare Disease Orphan Drugs*, 1, 1-12.

Freedman, A.M. (2020). Adapting to a new normal - again. *CureSMA Direction*, 31, 16.

Freedman, A.M. (2017). The spirit of Westtown School and my son, Jack. *The Westonian Magazine*, Summer, 2017, 50-51.

Freedman, A.M. (2016). Giving thanks for progress: The new SMA. *CureSMA Direction*, 27, 75.

Freedman, A.M. (2012). Connecting with the heart of home care: The Bayada Way Project, ten years later. *Caring Magazine*, 31 (6), 19-25.

Freedman, A.M. (2007). What it means to care. *Caring Magazine*, 26 (9), 10-14.

Freedman, A.M. (2005). On listening to what the children say. *CureSMA Direction*, 16, 48.

Baiada, J.M. & Freedman, A.M. (2005). Finding the heart of home care: The Bayada Way Project. *Caring Magazine*, 24 (10), 16-28.

- Freedman, A.M. (2004). On both sides of the therapy room. *Quest Magazine*, 11, 52-53.
- Trueman, C.A. & Murray, J.E. (2003). September 11th and home care: Connecting with our clients in times of uncertainty. An interview with Mark Baiada and Albert Freedman. *Caring Magazine*, 22, 34-41.
- Baiada, J.M. & Freedman, A.M. (2003). Searching for the heart of home care: The Bayada Way Project. *Caring Magazine*, 22, 10-13.
- Bach, J.R., Vega, J., Majors, J., & Freedman, A.M. (2003). Spinal Muscular Atrophy Type I Quality of life. *American Journal of Physical Medicine and Rehabilitation*, 82, 137-142.
- Freedman, A.M. (2003). Keeping hope alive. *Quest Magazine*, 10, 69-70.
- Freedman, A.M. (2002). Reaching out to family and friends: One family's story. *Quest Magazine*, 9, 39-41.
- Freedman, A.M. (2001). The future is now. In S.D. Klein & K. Shive (Eds.), *You will dream new dreams: Inspiring personal stories by parents of children with disabilities* (pp. 38-42). New York: Kensington Publishing.
- Freedman, A.M. (2001). Welcome to our home: An open letter to home care professionals. *Caring Magazine*, 20, 8-11.
- Coleman, H.L.K. & Freedman, A.M. (1996). Effects of a structured group intervention on the achievement of academically at-risk undergraduates. *Journal of College Student Development*, 37, 631-636.

## **PRESENTATIONS**

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- Freedman, A.M. (2024, June). Moving mountains: strategies for coping with rare disease. Keynote presentation at the HCU Network America, Denver, Colorado.
- Freedman, A.M. (2024, June). Meeting the challenge of rare disease in the family: 25 years of lessons learned. Keynote presentation at the 2<sup>nd</sup> International CTNBN1 Syndrome Conference, Ljubljana, Slovenia.
- Freedman, A.M. (2024, June). Meeting the challenge of rare disease: 25 years of lessons learned. Keynote presentation at the 2024 Annual Ataxia Conference, National Ataxia Foundation, Orlando, Florida.
- Freedman, A.M., DeFabio, D, Davis, M. (2024, April). Understanding and addressing the unique needs of rare disease patient advocacy leaders and communities. World Orphan Drug Congress, Boston, Massachusetts.
- Freedman, A.M. (2023, October). The future of genomics in newborn screening. Moderator for panel presentation at the World Orphan Drug Congress, Barcelona, Spain.
- Freedman, A.M. (2023, October). Supporting the mental health needs of patients and families affected by rare disease: What we know and what we are learning. Moderator for panel presentation at National Organization of Rare Disorders Breakthrough Summit, Washington, DC.
- Freedman, A.M. (2023, September). Coping with the Challenge of Rare Disease - With or Without a Diagnosis. Moderator for panel presentation at the Global Genes Rare Advocacy Summit, San Diego, CA.
- Freedman, A.M. (2023, September) Supporting Your Rare Community's Mental Health. Moderator for panel presentation at the Global Genes Rare Advocacy Summit, San Diego, CA.
- Freedman, A.M. (2023, July). Meeting the challenge of rare disease in the family: 25 years of lessons learned. Presentation at the Cystinosis Research Network Conference, Nashville, TN.
- Parsons, J., Taylor, J., Tarrant, S., Halanski, M., Edinger, J., Lewis, T., Freedman, A.M. (2023, June). Mapping the trajectory of treated SMA patients into the future. Panel presentation at the 4<sup>th</sup> Annual Clinical Care Conference for Professionals, CureSMA, Orlando, FL.

Freedman, A.M. (2023, May). Meeting the challenge of rare disease: 25 years of lessons learned. Keynote presentation at the World Orphan Drug Congress, Washington, DC.

Freedman, A.M. (2023, May). Industry's role in providing support beyond treatments to patients and families affected by rare disease: A case study. Moderator for panel presentation at the World Orphan Drug Congress, Washington, DC.

Freedman, A.M. (2023, May). Living with uncertainty. Moderator for panel presentation at the Living Rare, Living Stronger, Patient and Family Forum, National Organization of Rare Disorders (NORD), Washington, DC.

Freedman, A.M. (2023, May). Rare in the family: Family planning and decision-making. Panel presentation at the Living Rare, Living Stronger, Patient and Family Forum, National Organization of Rare Disorders (NORD), Washington, DC.

Freedman, A.M. (2023, April). Meeting the challenge of rare disease in the family: 25 years of lessons learned. Keynote presentation at the NephCure International Patient Summit, San Diego, CA.

Freedman, A.M. (2023, February). Mental health challenges and strategies for families affected by Duchenne Muscular Dystrophy. Presentation for the Jett Foundation, Plymouth, MA.

Freedman, A.M. (2022, August). Mental health for rare adults. Panel presentation at the 2022 Rare Patient Advocacy Summit, Global Genes, San Diego, CA.

Freedman, A.M., Akers, A., & O'Loughlin, C.B. (2022, July). Mental health support for rare disease caregivers, patients and professionals: Examining barriers and opportunities to advance emotional care, education and accessibility. Panel presentation at the World Orphan Drug Congress, Boston, MA.

Freedman, A.M., Fine, A., & O'Loughlin, C.B. (2022, May). Designing mental health solutions to address gaps in care. Presentation at the Seattle Rare Disease Conference, Seattle Children's Hospital Research Institute, Seattle, WA.

Freedman, A.M. (2022, January). Living a rare life: 25 years of lessons learned. Presentation at the 6<sup>th</sup> Annual ALD Standards of Care Conference, Adrenoleukodystrophy Alliance, New York, NY.

Freedman, A.M. (2021, September). Informing decision-making towards gene therapy. Presentation to Open Health Group, London, UK.

Freedman, A.M. (2021, September). Redefining resiliency. Presentation at the 2021 RARE Patient Advocacy Summit, Global Genes, Aliso Viejo, CA.

Rao, V., Mosher, P., Battista, V., Murrell, D., & Freedman, A.M. (2021, June). Special session: Mental health challenges in SMA-Affected patients and families, Symptoms, resources and solutions. Presentation at the 4<sup>th</sup> Annual Clinical Care Conference for Professionals, CureSMA, Elk Grove Village, IL.

Freedman, A.M. (2021, May). Building resilience in a time of unknowns. Presentation at the Living Rare, Living Stronger, Patient and Family Forum, National Organization of Rare Disorders (NORD), Washington, DC.

Freedman, A.M. (2021, April). Meeting the emotional and mental health needs of rare disease communities. Presentation for Global Genes, Aliso Viejo, CA.

Freedman, A.M. (2020, December). A rare holiday season: Mental wellness, the holidays and the COVID-19 pandemic. Presentation for the National Organization of Rare Disorders (NORD), Washington, DC.

Freedman, A.M. (2020, December). One year to live, 25 years later: The power of gratitude. Presentation for Amicus Therapeutics, Cranbury, NJ.

Freedman, A.M. (2020, November). Coping with the challenges of a rare disease: An international perspective. Presentation for SMA Russia, Moscow, Russia.

Freedman, A.M. (2020, November). Supporting siblings in SMA-affected families. Summit of Strength presentation for CureSMA, Elk Grove Village, IL.

Freedman, A.M. (2020, October). A parent's perspective on transition: 25 year of lessons learned. Presentation at the 21<sup>st</sup> Annual 21st Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care. Texas Children's Hospital, Houston, TX.

Freedman, A.M. (2020, October). Building resilience in families affected by neuromuscular disease. Presentation for SMA Australia, Brisbane, Australia.

Freedman, A.M. (2020, September). Supporting the emotional health of individuals affected by Friedreich's Ataxia. Presentation for Friedreich's Ataxia Research Alliance, Downingtown, PA.

Freedman, A.M. (2020, June). Fostering hope and strengthening families facing the challenges of rare disease. Presentation for Retrophin, Inc., San Diego, CA.

Freedman, A.M. & VanderVer, A. (2020, June). Maintaining physical and mental health during the COVID-19 pandemic. Presentation for the Global Leukodystrophy Initiative, Rare Diseases Clinical Research Network, National Center for Advancing Translational Sciences, Children's Hospital of Philadelphia, Philadelphia, PA.

Freedman, A.M. (2020, June). Life after diagnosis: 25 years of lessons learned. Presentation at the Annual Conference of CureSMA, Elk Grove Village, IL.

Freedman, A.M. (2020, May). Supporting the emotional health of our SMA-affected families in uncertain times. Summit of Strength presentation for CureSMA, Elk Grove Village, IL.

Hobby, K., Schroth, M. & Freedman, A.M. (2020, May). Coping with Dual Challenges: An SMA Diagnosis & COVID-19. Presentation for CureSMA, Elk Grove, IL.

Summar, M., Wiedermann, B. & Freedman, A.M. (2020, March). A rare response: Addressing the COVID-19 pandemic. Presentation for the National Organization of Rare Disorders, Washington, DC.

Alderfer, M.A., Taggi Pinto, A., Hildenbrand, A. K., Freedman, A., Finkel, R. Scavina, M. & Butchbach, M. E. R. (2019, August). Preliminary adaptation of the PAT for use with families of children with Spinal Muscular Atrophy. In Alderfer, M.A. & Kazak, A.E (Chairs), Screening Families for Psychosocial Risk: Recent Advances in the Psychosocial Assessment Tool (PAT). Presentation at the American Psychological Association Annual Convention, Chicago, IL.

Freedman, A.M. (2019, June). Supporting the emotional health of our SMA-affected family members. Presentation at the 26<sup>th</sup> Annual Conference of CureSMA (Spinal Muscular Atrophy), Anaheim, CA.

Freedman, A.M. (2019, June). Managing relationships: Raising a rare child. Presentation at the Living Rare, Living Stronger, Patient and Family Forum, National Organization of Rare Disorders (NORD), Houston, TX.

Freedman, A.M. (2019, June). Self-care and emotional health of the caregiver. Presentation at the Patient and Family Forum, National Organization of Rare Disorders (NORD), Houston, TX.

Freedman, A.M. (2016, June). Living with spinal muscular atrophy. Presentation at the James Wilson Lab, Orphan Disease Center, Gene Therapy Program, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA.

Freedman, A.M. (2015, April). One year to live, twenty years later: The lasting power of faith, hope, & love. Keynote presentation at the 2015 Reflection and Consultation Conference, Center for Spiritual Care and Pastoral Formation, Nemours/A.I. DuPont Hospital for Children, Wilmington, DE

Freedman, A.M. (2014, August). Coping with the Challenges of SMA. Keynote presentation at the Wisconsin State Conference on Spinal Muscular Atrophy, University of Wisconsin School of Medicine and Public Health, Madison WI

Baiada, J.M. & Freedman, A.M. (2013, November). Connecting with the heart of home care: The importance of a values-driven culture. Presentation at the Annual Meeting of the National Association of Home Care and Hospice, Washington, DC

Freedman, A.M. (2013, October). One year to live, seventeen years later: Why hope matters. Keynote presentation at the 10th Annual Nursing of Children Network Regional Conference, Society of Pediatric Nurses, Wilmington, DE

Freedman, A.M. (2011, November). Family caregivers: Fathers' perspectives. Moderator for panel discussion at the 5th Annual Special Children, Special Needs Pediatric Conference, University of Delaware, Newark, DE

Freedman, A.M. (2009, June). Effects of having a chronically ill child on families. Presentation at the 5th Annual conference of the 5th Annual VACTERL Network Family Conference, Philadelphia, PA

Freedman, A.M. (2008, November). What patients and families need. Annual conference of the Delaware Association of Home & Community Care, Dover, DE

Freedman, A.M. (2007, October). What it means to care. Keynote presentation at the 1st Annual Special Children, Special Needs Pediatric Nurses Conference, University of Delaware, Newark, DE

Freedman, A.M. (2006, April). Why hope matters. Opening presentation at the 16th Annual Convention of the Society of Pediatric Nurses, Orlando, FL

Freedman, A.M. (2005, October). One year to live, ten years later. Dean's Lecture, School of Nursing, University of Pennsylvania, Philadelphia, PA

Freedman, A.M. (2005, June). Talk it out. Workshop for affected children at the 12th Annual Conference of Families of Spinal Muscular Atrophy, Philadelphia, PA

Freedman, A.M. (2005, May). Nurses and hope. Lecture, Department of Nursing, duPont Hospital for Children, Wilmington, DE

Freedman, A.M. (2005, April). The Bayada Way: Our mission, vision, values and beliefs. Keynote presentation at the Annual Meeting of Bayada Nurses, Baltimore, MD

Freedman, A.M. (2004, November). Why hope matters. Keynote presentation at the 1st Annual Nursing of Children Network Regional Conference, Society of Pediatric Nurses, Philadelphia, PA

Baiada, J.M. & Freedman, A.M. (2004, October). Building a community of home health care professionals. Presentation at the 4th World Congress on Home Care and Hospice, Phoenix, AZ

Freedman, A.M. (2004, June). Life after diagnosis. Presentation at the 11th Annual Conference of Families of Spinal Muscular Atrophy, Chicago, IL

Freedman, A.M. (2004, April). Searching for The Bayada Way. Keynote presentation at the Annual Meeting of Bayada Nurses, Philadelphia, PA

Baiada, J.M. & Freedman, A.M. (2003, October). Leading with the heart in home care & hospice services. Presentation at the 3rd World Congress on Home Care and Hospice, Orlando, FL

Freedman, A.M. (2003, June). Keeping hope alive. Presentation at the 10th Annual Conference of Families of Spinal Muscular Atrophy, Washington, DC

Freedman, A.M. (2003, May). The Bayada Way Project. Keynote presentation at the Annual Meeting of Bayada Nurses, Atlantic City, NJ

Freedman, A.M. (2002, June). Staying positive in the face of adversity. Presentation at the 9th Annual Conference of Families of Spinal Muscular Atrophy, Chicago, IL

Freedman, A.M. (2001, December). The non-disciplinary school intervention team. In P. Libman (Chair), Balancing Health and Discipline Oriented Approaches to Student Substance Abuse. Presentation at the Annual National Conference of the Association of Boarding Schools, Chicago, IL

- Freedman, A.M. (2001, June). How families cope with neuromuscular disease. Presentation at the 8th Annual Conference of Families of Spinal Muscular Atrophy, Chicago, IL
- Freedman, A.M. (2001, April). The future is now. In S. Klein (Chair), Parents: You can dream new dreams. Presentation at the New York Metro Abilities Expo, Edison, NJ
- Freedman, A.M. (2001, March). The gift of another day: Medically fragile children and their caregivers. Featured presentation at the Annual Conference of the Delaware Valley Association for the Education of Young Children, Philadelphia, PA
- Freedman, A.M. (2001, February). Life after diagnosis: Coping with the challenge of a child's life-threatening medical condition. Presentation at the Ken-Crest National Conference on Children Who are Medically Complex or Technology Dependent, Philadelphia, PA
- Freedman, A.M. (2000, October). Coping with neuromuscular disease. Presentation at the 2nd Annual Medical Conference on Spinal Muscular Atrophy, duPont Hospital for Children, Wilmington, DE
- Freedman, A.M. (2000, June). Life after diagnosis. Presentation at the Annual National Conference of Families of Spinal Muscular Atrophy, St. Louis, MO
- Freedman, A.M. (2000, February). The special needs of mothers and fathers with special needs children. Presentation at the Annual Conference of the Delaware Valley Association for the Education of Young Children, Philadelphia, PA
- Freedman, A.M. (1999, September). Fragile children, strong families: Coping with spinal muscular atrophy. Presentation at the 1st Annual Medical Conference on Spinal Muscular Atrophy, duPont Hospital for Children, Wilmington, DE
- Freedman, A.M. (1999, February). Jack's story. In R. Naseef (Chair), The father factor: A session for fathers of children with special needs. Presentation at the Annual Conference of the Delaware Valley Association for the Education of Young Children, Philadelphia, PA
- Freedman, A.M. (1997, July). Peer culture in childhood and adolescence: Challenges and opportunities for Quaker school educators. In L.J. Farrow (Chair), Peer culture. Symposium conducted at the 2nd International Conference on Quaker Education, Westtown School, Westtown, PA
- Freedman, A. M. & Coleman, H.L.K. (1996, August). Measuring academic self-efficacy in undergraduates. Poster session presented at the Annual Meeting of the American Psychological Association, Toronto, Ontario, Canada.
- Coleman, H.L.K. & Freedman, A.M. (1995, August). Effects of a multicomponent group intervention on the self-efficacy and academic achievement of at-risk undergraduates. Poster session presented at the Annual Meeting of the American Psychological Association, New York, NY
- Freedman, A. M. (1994, February). Childhood anger and aggression: Misbehavior or behavior? Keynote address at the 6th Annual Kindergarten Conference, Wisconsin Early Childhood Association, Green Bay, WI
- Freedman, A.M. (1993, October). Understanding and working with the angry child. Presentation at the Annual Conference of the Wisconsin Early Childhood Association, Madison, WI
- Freedman, A.M. (1993, August). The importance of integrating science and practice in counseling psychology training programs. Poster presentation at the Annual Meeting of the American Psychological Association, Toronto, Ontario, Canada.
- Freedman, A.M. (1992, November). Aggression and the young child: Roots, risks, and responses. Presentation at the Annual Conference of the Wisconsin Early Childhood Association, Oshkosh, WI