RESOURCE GUIDE & INFORMATION



Huntington's Disease Society of America

MASSACHUSETTS & RHODE ISLAND CHAPTER



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MASSACHUSETTS COMMUNITY ACTION AGENCIES

Provides assistance with GED and ESL education, job training, head start and day care, low-income home energy assistance programs, weatherization assistance programs, homeless prevention programs, senior services, temporary emergency food assistance programs, and housing support programs. Available services vary from agency to agency.

Please reference the list below to find your Community Action Agency. You can also search for your local Community Action Agency here: https://www.masscap.org/agencies/

Action for Boston Community Development, Inc. (ABCD)

178 Tremont St.
Boston, MA 02111
Phone: 617-357-6000 Fax: 617-482-4859
www.bostonabcd.org
Cities/Towns in the Service Area: Boston, Brookline, Everett, Malden, Medford, Melrose, Newton, Stoneham, Winchester, Woburn

Action, Inc. (Action)

180 Main St.
Gloucester, MA 01930
Phone: 978-282-1000 Fax: 978-283-0523
www.actioninc.org
Cities/Towns in the Service Area: Essex, Gloucester, Hamilton, Ipswich, Manchester, Rockport, Wenham

Berkshire Community Action Council, Inc. (BCAC)

1531 East Street
Pittsfield, MA 01201
Phone: 413-445-4503 Fax: 413-447-7871
www.bcacinc.org
Cities/Towns in the Service Area: Adams, Alford, Becket, Cheshire, Clarksburg, Dalton, Egremont, Florida, Great Barrington, Hancock, Hinsdale, Lanesborough, Lee, Lenox, Monterey, Mount Washington, New Ashford, New Marlborough, North Adams, Otis, Peru, Pittsfield, Richmond, Sandisfield, Savoy, Sheffield, Stockbridge, Tyringham, Washington, West Stockbridge, Williamstown, and Windsor

Cambridge Economic Opportunity Committee, Inc. (CEOC)

11 Inman St.
Cambridge, MA 02139
Phone: 617-868-2900 Fax: 617-868-2395
https://ceoccambridge.org/
Cities/Towns in the Service Area: Cambridge

Citizens for Citizens, Inc. (CFC)

264 Griffin St.
Fall River, MA 02724
Phone: 508-679-0041 Fax: 508-324-7503
www.cfcinc.org
Cities/Towns in the Service Area: Attleboro, Berkley, Dighton, Fall River, Freetown, Lakeville, Rehoboth, Seekonk, Somerset, Swansea, Taunton, Westport

Community Action Agency of Somerville, Inc. (CAAS)

66-70 Union Square, #104
Somerville, MA 02143
Phone: 617-623-7370 Fax: 617-628-2512
www.caasomerville.org
Cities/Towns in the Service Area: Somerville

Community Action Committee of Cape Cod & Islands, Inc. (CACCI)

372 North St.
Hyannis, MA 02601
Phone: 508-771-1727 Fax: 508-775-7488
www.cacci.cc
Cities/Towns in the Service Area: Barnstable, Bourne, Brewster, Chatham, Dennis, Edgartown, Falmouth, Gayhead, Gosnold, Harwich, Hyannis, Mashpee, Nantucket, Oak Bluffs, Provincetown, Sandwich, Tisbury, Truro, Vineyard Haven, Wareham, and Yarmouth

Community Action, Inc. (CAI)

3 Washington Square
Haverhill, MA 01830
Phone: 978-373-1971 Fax: 978-469-8392
www.communityactioninc.org
Cities/Towns in the Service Area: Amesbury, Boxford, Georgetown, Groveland, Haverhill, Merrimac, Newbury, Newburyport, Rowley, Salisbury, West Newbury

Community Action Programs Inter-City, Inc. (CAPIC)

100 Everett Ave. #14
Chelsea, MA 02150
Phone: 617-884-6130 Fax: 617-889-8110
www.capicinc.org
Cities/Towns in the Service Area: Chelsea, Melrose, Revere, Wakefield, Winthrop

Community Teamwork, Inc. (CTI)

155 Merrimack St.
Lowell, MA 01852
Phone: 978-459-0551 Fax: 978-453-9128
www.commteam.org
Cities/Towns in the Service Area: Acton, Amesbury, Andover, Arlington, Ashby, Ayer, Bedford, Belmont, Beverly, Billerica, Boxford, Burlington, Carlisle, Chelmsford, Danvers, Dracut, Dunstable, Essex, Everett, Georgetown, Gloucester, Groton, Groveland, Hamilton, Haverhill, Ipswich, Lawrence, Lexington, Littleton, Lowell, Lynnfield, Malden, Manchester, Marblehead, Medford, Melrose, Merrimac, Methuen, Middleton, Nahant, Newbury, Newburyport, North Andover, North Reading, Peabody, Pepperell, Reading, Rockport, Rowley, Salem, Salisbury, Saugus, Stoneham, Swampscott, Tewksbury, Topsfield, Tyngsborough, Wakefield, Waltham, Watertown, Wenham, West Newbury, Westford, Wilmington

Lynn Economic Opportunity Council (LEO)

181 Union St. #209
Lynn, MA 01901
Phone: 781-581-7220 Fax: 781-581-5320
www.leoinc.org
Cities/Towns in the Service Area: Lynn, Lynnfield, Marblehead, Nahant, Saugus, Swampscott, Wakefield

Making Opportunity Count (MOC)

601 River St.
Fitchburg, MA 01420
Phone: 978-345-7040 Fax: N/A
www.mocinc.org
Cities/Towns in the Service Area: Ashburnham, Ashby, Athol, Ayer, Barre, Berlin, Bolton, Clinton, Fitchburg, Gardner, Groton, Hardwick, Harvard, Hubbardston, Lancaster, Leominster, Lunenberg, New Braintree, Petersham, Phillipston, Princeton, Royalston, Shirley, Sterling, Templeton, Townsend, Westminster, Winchendon

South Middlesex Opportunity Council, Inc. (SMOC)

7 Bishop St.
Framingham, MA 01702
Phone: 508-872-4853 Fax: 508-620-2310
www.smoc.org
Cities/Towns in the Service Area: Acton, Ashland, Bellingham, Blackstone, Boxborough, Concord, Dover, Framingham, Georgetown, Grafton, Haverhill, Holliston, Hopedale, Hudson, Lincoln, Littleton, Marlborough, Maynard, Medfield, Medway, Mendon, Milford, Millbury, Millis, Natick, Northborough, Northbridge, Sherborn, Shrewsbury, Southborough, Stoneham, Stow, Sudbury, Upton, Uxbridge, Wayland, Wellesley, Weston

Springfield Partners for Community Action, Inc. (SPCA)

721 State St. 2nd Floor
Springfield, MA 01109
Phone: 413-263-6500 Fax: 413-263-6511
www.springfieldpartnersinc.com
Cities/Towns in the Service Area: Springfield

Quincy Community Action Programs, Inc. (QCAP)

1509 Hancock St.
Quincy, MA 02169
Phone: 617-479-8181 Fax: 617-479-7228
www.qcap.org
Cities/Towns in the Service Area: Braintree, Hull, Milton, Quincy, Weymouth

South Shore Community Action Council, Inc. (SSCAC)

71 Obery St.
Plymouth, MA 02360
Phone: 508-747-7575
Fax: 508-747-1250
www.sscac.org
Cities/Towns in the Service Area: Barnstable, Bourne, Brewster, Carver, Chatham, Chilmark, Cohasset, Dennis, Duxbury, Eastham, Falmouth, Gayhead, Gosnold, Halifax, Hanover, Harwich, Hingham, Hull, Hyannis, Kingston, Marshfield, Mashpee, Middleborough, Nantucket, Norwell, Oak Bluffs, Orleans, Pembroke, Plymouth, Plympton, Provincetown, Sandwich, Scituate, Truro, Wareham, Wellfleet, West Tisbury, Yarmouth

Worcester Community Action Council, Inc. (WCAC)

18 Chestnut St.
Worcester, MA 01608
Phone: 508-754-1176 Fax: 508-754-0203
www.wcac.net
Cities/Towns in the Service Area: Auburn, Boylston, Brimfield, Brookfield, Charlton, Clinton, Douglas, Dudley, East Brookfield, Grafton, Granville, Hardwick, Holden, Holland, Hopedale, Leicester, Mendon, Milford, Millbury, Millville, Monson, New Braintree, North Brookfield, Northborough, Northbridge, Oakham, Oxford, Palmer, Paxton, Rutland, Shrewsbury, Southbridge, Spencer, Sterling, Sturbridge, Sutton, Upton, Uxbridge, Wales, Warren, Webster, West Boylston, West Brookfield, Westborough, Worcester

Valley Opportunity Council, Inc. (VOC)

300 High St.
Holyoke, MA 01040
Phone: 413-552-1554 Fax: 413-552-1558
www.valleyopp.com
Cities/Towns in the Service Area: Agawam, Ashby, Blandford, Brimfield, Chester, Chicopee, East Longmeadow, Granby, Granville, Hampden, Holland, Holyoke, Longmeadow, Ludlow, Monson, Montgomery, Palmer, Russell, South Hadley, Southwick, Springfield, Tolland, Wales, West Springfield, Westfield, Wilbraham

People Acting in Community Endeavors, Inc. (PACE)

166 William Street
New Bedford, MA 02742
Phone: 508-999-9920
Fax: 508-999-3728
http://www.paceinfo.org
Cities/Towns in the Service Area: Acushnet, Darmouth, Fairhaven, Marion, Mattapoiset, New Bedford, Rochester

Self Help, Inc. (SHI)

45 Pearl St.
Brockton, MA 02301
Phone: 508-588-0447 Fax: 508-588-1266
www.selfhelpinc.org
Cities/Towns in the Service Area: Abington, Attleboro, Avon, Bridgewater, Brockton, Canton, Dedham, Easton, Foxborough, Franklin, Hanson, Holbrook, Mansfield, Middleborough, Needham, Norfolk, North Attleboro, Norton, Norwood, Plainville, Randolph, Raynham, Rockland, Stoughton, West Bridgewater, Westwood, Whitman, Wrentham

Greater Lawrence Community Action Council (GLCAC)

305 Essex St.
Lawrence, MA 01840
Phone: 978-681-4900 Fax: 978-681-4949
www.glcac.org
Cities/Towns in the Service Area: Andover, Lawrence, Methuen, and North Andover

Community Action of Pioneer Valley

393 Main St.
Greenfield, MA 01301
Phone: 413-774-2318 Fax; 413-773-3834
Cities/Towns in the Service Area: Agawam, Amherst, Ashfield, Athol, Belchertown, Bernardston, Blandford, Buckland, Chester, Chesterfield, Colrain, Conway, Cummington, Easthampton, Erving, Gill, Goshen, Granby, Granville, Greenfield, Hadley, Heath, Huntington, Leverett, Leyden, Ludlow, Middlefield, Monroe, Montague, Montgomery, Northampton, Northfield, Orange, Petersham, Phillipston, Plainfield, Rowe, Royalston, Russell, Shelburne, South Hadley, Southampton, Southwick, Sunderland, Tolland, Ware, Wendell, West Springfield, Westfield, Westhampton, Whately, Williamsburg

North Shore Community Action Programs, Inc. (NSCAP)

119 Rear Foster St. Building 13
Peabody, MA 01960
Phone: 978-531-0767 Fax: 978-531-1012
www.nscap.org
Cities/Towns in the Service Area: Beverly, Danvers, Marblehead, Middleton, Peabody, Salem, Topsfield

RHODE ISLAND

Provides assistance with GED and ESL education, job training, head start and day care, low-income home energy assistance programs, weatherization assistance programs, homeless prevention programs, senior services, temporary emergency food assistance programs, and housing support programs. Available services vary from agency to agency.
Please reference the list below to find your Community Action Agency. You can also search for your local Community Action Agency here: https://www.ricommunityaction.org/find-your-community-action-agency/

Blackstone Valley Community Action Program

32 Goff Avenue
Pawtucket, Rhode Island 02860
Phone: 401-723-4520 Fax: 401-725-6550
https://bvcap.org/
Cities/Towns in the Service Area: Pawtucket, Central Falls, Lincoln, Cumberland, Woonsocket

Comprehensive Community Action Program

311 Doric Avenue
Cranston, RI 02910-2903
Phone: 401-467-9610 Fax: N/A
https://www.comcap.org/
Cities/Towns in the Service Area: Cranston, Foster, Scituate, Coventry

East Bay Community Action Program

Location 1: 19 Broadway
Newport, RI 02840
Phone: 401-847-7821 Fax: N/A
Cities/Towns in the Service Area: Tiverton, Little Compton, Portsmouth, Middletown, Newport, Jamestown
Location 2: 100 Bullocks Point Ave.
Riverside, RI 02915
Phone: 401-437-1000 Fax: N/A
Cities/Towns in the Service Area: East Providence, Barrington, Warren, Bristol
Both Locations: www.ebcap.org

Community Action Partnership of Providence County

518 Hartford Avenue.
Providence, RI 02909
Phone: 401-273-2000 Fax: 401-273-2007
https://cappri.org/
Cities/Towns in the Service Area: All of Providence County

Community Care Alliance

800 Clinton St.
Woonsocket, RI 02895
Phone: 401-235-7000 Fax: N/A
https://www.communitycareri.org/
Cities/Towns in Service Area: Woonsocket

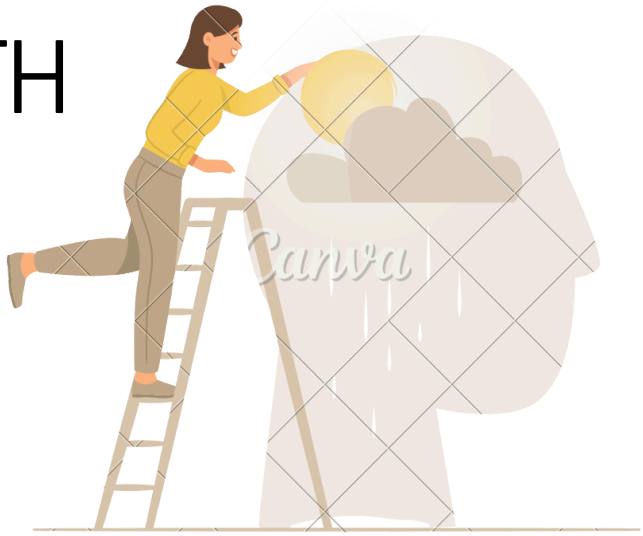
Tri-County Community Action Agency

Location 1: 1126 Hartford Avenue
Johnston, RI 02919
Phone: 401-351-2750 Fax: N/A
Cities/Towns in Service Area: North Providence, Johnston, Smithfield, North Smithfield, Burrillville, Glocester
Location 2: 1935 Kingstown Rd.
Wakefield, RI 02879
Phone: 401-789-3016 Fax: N/A
Cities/Towns in Service Area: Exeter, Charlestown, Narragansett, Westerly, Hopkinton, North Kingstown, South Kingstown, Richmond, West Greenwich, New Shoreham

Westbay Community Action, Inc.

487 Jefferson Blvd
Warwick, RI 02886
Phone: 401- 732-4666 Fax: N/A
https://westbaycap.org/
Cities/Towns in the Service Area: Warwick, West Warwick, East Greenwich

MENTAL HEALTH & SUBSTANCE ABUSE RESOURCES



MASSACHUSETTS AND RHODE ISLAND

1 SAMHSA NATIONAL HELPLINE

SAMHSA's National Helpline, 1-800-662-HELP (4357), (also known as the Treatment Referral Routing Service) or TTY: 1-800-487-4889 is a confidential, free, 24-hour-a-day, 365-day-a-year, information service, in English and Spanish, for individuals and family members facing mental and/or substance use disorders. This service provides referrals to local treatment facilities, support groups, and community-based organizations. Callers can also order free publications and other information. You can also search for treatment services here:
https://findtreatment.gov/

2 HDSA TELEHEALTH THROUGH AMWELL

HDSA's FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home. To utilize HDSA's free telehealth portal, visit www.hdsa.amwell.com or download the free Amwell® app and use the Service Key: HDSA to access the Huntington's disease practice. On the site, patients can schedule appointments with social workers and psychologists licensed in their state. The sessions are free for families affected by HD, and no insurance is required. You can have up to 8 sessions per year.

3 HDSA SUPPORT GROUPS

Regional, Virtual and In Person:
https://massri.hdsa.org/about/new-england-region-support-groups
National, Virtual: https://hdsa.org/find-help/community-social-support/hdsa-support-groups/

MASSACHUSETTS-ONLY RESOURCES

1 MASSACHUSETTS BEHAVIORAL HEALTH HELP LINE (BHHL)

Can connect you directly to clinical help, when and where you need it. Available 24 hours per day, 7 days per week, 365 days per year (including holidays). It's free, confidential, and no health insurance is required. Real-time interpretation in 200+ languages. Deaf or hard of hearing? Contact MassRelay at 711

- Call or text 833-773-2445
- Live chat available at: https://www.masshelpline.com/
- Search the behavioral health resource directory at: https://www.masshelpline.com/MABHHLTreatmentConnectionResourceDirectory

2 MOBILE CRISIS/EMERGENCY INTERVENTION

If you or a family member are experiencing a mental health or substance use disorder crisis and feel like you need help within one hour, you can call 1-877-382-1609. Provides crisis assessment, intervention, and stabilization services. Instead of going to the emergency room, you can get these services in your home or at other locations in the community. MCI (Mobile Crisis Intervention) services are available to people of all ages who are covered by MassHealth or Medicare. You can also get these services if you are uninsured. If you have a different health plan, you still may be able to get MCI services.

3 NAMI COMPASS

COMPASS is the information and referral helpline at NAMI Massachusetts. They provide resources and support to help people navigate the complex mental health system and problem solve in difficult circumstances. Trained Navigators are available to answer a wide range of questions and refer to community resources.
The COMPASS helpline is available Monday through Friday, 9 am – 5 pm. Call the helpline at 617-704-6264 or 1-800-370-9085, or email them at compass@namimass.org.

4 MASSACHUSETTS SUBSTANCE USE HELPLINE

The Helpline is the only statewide, public resource for finding substance use treatment and recovery services. Helpline services are free and confidential. Caring, trained Specialists will help you understand the treatment system and your options. Call the helpline for live help at 1-800-327-5050 or search the directory online at: https://helplinema.org/

5 THERAPY MATCHER REFERRAL SERVICE

Free telephone referral service that connects people with licensed independent clinical social workers (LICSWs) across Massachusetts.

- www.TherapyMatcher.org
- (617) 720-2828 or (800) 242-9794
- info@therapymatcher.org

RHODE ISLAND-ONLY RESOURCES

1 BH LINK

If you are struggling with alcohol or drug use, help is waiting across Rhode Island. All you have to do is reach out. There are many treatment and recovery options to help you with a plan that will work for you. Call 988 to learn more and connect with a BH Link trained crisis counselor. For walk-in behavioral health services, the BH Link Walk-In/Drop Off Triage Center is open 24/7 to connect people to immediate, stabilizing emergency behavioral health services and long-term care and recovery supports. BH Link is located at 975 Waterman Ave., East Providence, RI. People with moderate to severe opioid use disorder (OUD) can access telehealth service for initiation of buprenorphine treatment 24 hours a day, seven days a week. Call Rhode Island's Buprenorphine Hotline 401-606-5456.

2 UNITED WAY OF RHODE ISLAND AND CVS HEALTH FOUNDATION

Working together to help those impacted by the opioid crisis. Our goal is to connect Rhode Islanders with treatment resources, increase addiction awareness, and find options that work:

- 2-1-1 staff received specialized training in answering addiction-related calls.
- We've added three-way calling with Anchor Recovery, a comprehensive substance abuse treatment organization, to assist in urgent situations.
- The 2-1-1 Outreach RV travels to locations throughout the state, including monthly visits to CVS stores, raising awareness and bringing addiction recovery services directly into communities.

3 ANCHOR RECOVERY

As an Anchor Recovery Community Center member, you will have access to our recovery community centers, located in Providence and Warwick, RI. We provide a safe, welcoming environment for all individuals in recovery from substance use disorders. (401) 889-5770

4 MENTAL HEALTH ASSOCIATION OF RHODE ISLAND

Our mission is to promote and nourish mental health through advocacy, education, and policy development. The Mental Health Association of Rhode Island is the watchdog of the mental health community. We increase consumers' access to treatment and services, and improve the lives of people touched by mental illness. Our work includes: Policy and Advocacy, Research, Awareness and Education, and Diversity, Equity, and Inclusion. You can review the MHARI resource guide here:

https://mhari.org/resources/

HUNTINGTON'S DISEASE SPECIFIC RESOURCE WEBSITES

There are several valuable resources available for individuals and families affected by Huntington's disease. These resources can provide information, support, and assistance in managing the challenges of the condition. Here are some of the key Huntington's disease resources:

Huntington's Disease Society of America (HDSA)

https://hdsa.org/
HDSA is a national non-profit organization that provides support, advocacy, and resources for individuals and families affected by HD. They offer information about the disease, support groups, educational materials, and opportunities to get involved in research and fundraising efforts.

Huntington's Disease Youth Organization (HDYO)

https://en.hdyo.org/
HDYO focuses on supporting young individuals impacted by Huntington's disease. They offer resources, education, and events specifically tailored to young people who have a family history of the condition.

Huntington's Disease Clinical Trials Database

https://clinicaltrials.gov/
This database provides information on ongoing and completed clinical trials related to Huntington's disease. It allows individuals to search for clinical trials and potentially participate in research studies.

Huntington's Disease Outreach Project for Education at Stanford

https://web.stanford.edu/group/hopes/cgi-bin/hopes_test/ HOPES is a resource providing comprehensive information about Huntington's disease, including research updates, treatment options, and scientific breakthroughs.

National Institute of Neurological Disorders and Stroke (NINDS)

https://hdsa.org/

HDSA is a national non-profit organization that provides support, advocacy, and resources for individuals and families affected by HD. They offer information about the disease, support groups, educational materials, and opportunities to get involved in research and fundraising efforts.

Help 4 HD

https://www.help4hd.org/

Help 4 HD's mission is to educate the world about Huntington's disease (HD) and Juvenile Huntington's disease (JHD) through its multimedia communications platform. Through live events, Help 4 HD Radio, Help 4 JHD Radio, symposia, conferences, publications, and support groups, Help 4 HD brings education, information, and resources to the global community, partnering with medical professionals, researchers, institutions and industry for the most current and credible information and resources available.

HDSA Telehealth

HDSA's FREE Telehealth Program, makes it easy for you to talk to mental health therapists from the comfort of your home. To utilize HDSA's free telehealth portal, visit www.hdsa.amwell.com or download the free Amwell® app and use the Service Key: HDSA to access the Huntington's disease practice. On the site, patients can schedule appointments with social workers and psychologists licensed in their state. The sessions are free for families affected by HD, and no insurance is required.

HDSA Support Groups- Massachusetts



https://massri.hdsa.org/about/new-england-region-support-groups

HD Reach

https://www.hdreach.org/

HD Reach is working to improve the care and quality of life for those affected by Huntington's disease. Founded as a nonprofit in 2009, we provide connections to medical providers, referrals to local services, care management, family support, education, and anonymous genetic testing.

Champions for HD

https://www.championsforhd.org/

Champions for HD is a non-profit in the fight against Huntington's Disease. Founded in 2018 by Shelby Lentz, who drew inspiration from the Rocky Balboa movies, this non-profit aims to not only fight for a cure for Huntington's Disease, and Juvenile Huntington's Disease, but to help those who are struggling with this disease with financial aid.

HD Genetics

https://hdgenetics.com/

HD Genetics understands that the decision to pursue genetic testing for Huntington's disease (HD) can be difficult. We offer you the ability to undergo genetic counseling and testing with a licensed HD genetics expert from the comfort & convenience of your own home! HD Genetics also offers options to test under a concealed identity for individuals who wish to test anonymously.

Enroll-HD

https://www.enroll-hd.org/

Enroll-HD is a clinical research platform and the world's largest observational study for Huntington's disease families. It is a resource for the entire HD community, including families, clinicians, researchers, advocates, and anyone else who has a connection to or an interest in HD.

HD BUZZ

https://en.hdbuzz.net/

Huntington's disease research news. In plain language. Written by scientists. For the global HD community.

HD Clarity

https://hdclarity.net/
A multi-site cerebrospinal fluid collection initiative to facilitate therapeutic development for Huntington's disease.

HD TrialFinder

https://hdsa.org/hd-research/hd-trial-finder/
HD Trialfinder is a clinical trials matching service: a way for individuals with Huntington's disease, caregivers, healthy volunteers, and physicians to connect with current research studies. It includes an easy-to-use website and free call center staffed by trained HD clinical trial navigators

Honestly HD

HonestlyHD.com





GENETIC TESTING INFORMATION

Thinking about getting tested? Before proceeding with genetic testing for Huntington's disease, consider the potential psychological and emotional impact of the results, regardless of the outcome. Genetic testing may have implications not only for you but also for your family members. It is crucial to seek appropriate counseling and support throughout the process. Remember that genetic testing is a personal decision, and there is no pressure to undergo testing if you are not ready. It's best to discuss your concerns and questions with a healthcare professional who can guide you through the process and help you make an informed decision.

Before you get tested: *Please download this FREE packet for more information on IF getting tested is right for you.*
https://hdsa.org/wp-content/uploads/2015/03/GeneticTesting.pdf

COMMON WAYS TO GET TESTED



Neurologist or Movement Disorder Specialist

Neurologists and movement disorder specialists often have experience in diagnosing and managing Huntington's disease. They can help you understand the symptoms and whether genetic testing is appropriate for your situation.



Huntington's Disease Centers of Excellence

Some specialized centers, known as Huntington's Disease Centers of Excellence, offer comprehensive care for individuals and families affected by the disease. These centers may provide genetic testing services as part of their care offerings.



University Hospitals and Medical Centers

Many university-affiliated hospitals and medical centers have departments specializing in genetics and neurology, where you can access genetic testing for Huntington's disease.



National Institutes of Health (NIH) and Clinical Trials

The NIH and other research institutions may offer genetic testing as part of clinical trials or research studies related to Huntington's disease. Participating in such studies may provide access to genetic testing.



Genetic Testing Laboratories

Some commercial genetic testing companies offer direct-to-consumer testing for Huntington's disease. However, it is essential to exercise caution when using these services, as genetic testing for Huntington's disease can have significant emotional and psychological implications. Consulting with a genetic counselor or healthcare professional beforehand is strongly recommended.

HOW MUCH DOES TESTING COST?

The cost of testing varies from center to center. Some centers are research facilities and will perform the test free of charge for those involved in their studies, some have sliding fee scales, and others charge anywhere from $315 to $1,500.

Testing Centers		
Rhode Island	**Massachusetts**	**Virtual/Other**
Butler Hospital Movement Disorders Program Providence, RI 02906 401-455-6669	**HDSA Center of Excellence at Beth Israel Deaconess Medical Center** 330 Brookline Ave, Kirstein 2 Boston, MA 02115 Phone number to make appointments: 617-667-0519	**HD Genetics** hdgenetics.com 877-434-3639
Department of Neurology Rhode Island Hospital, Movement Disorders Providence, RI 02903 401-444-6528	**HDSA Center of Excellence Huntington's Disease Testing Center, Massachusetts General Hospital** 114 16th Street, East Bldg. 114, Suite 201 Charlestown, MA 02129 617-726-5732	**UCONN Health Center for HD** 10 Talcott Notch Road Farmington CT 06520 860-679-6775
	Boston Medical Center/BU Boston, MA 02118 For an appointment: 617-414-4841	**Albany Medical Center** Albany NY, 12208 518-262-5120

REPRODUCTIVE GENETIC TESTING CENTERS



Rhode Island/Connecticut	Massachusetts
Women and Infants Hospital Prenatal Diagnosis Center 101 Plain Street 6th Floor Providence, RI 02905 401-453-7510	**Massachusetts General Hospital** 55 Fruit Street Boston, MA 02114-2696 617-724-9009
UCONN Fertility 2 Batterson Park road Farmington CT 06032 844-HOPEIVF 844-467-3483	**BIDMC Pregnancy** 330 Brookline Avenue Boston, MA 02215 617-667-0475
	Boston Children's Hospital Maternal Fetal Care Center 300 Longwood Ave. Boston, MA 02115 617-355-6512
	Boston IVF 130 2nd Ave, Waltham, MA, 02451 (888) 300-2483

HD-SPECIFIC PROVIDERS

PHYSICAL THERAPY

Sarah Crandall Zoeller PT, DPT, NCS
101 Main Street, Ste 101, Medford, MA 02155
scrandall@partners.org
Spaulding Rehabilitation Hospital - Medford
781-391-7518

Lisa Walkin , PT MS GCS CEEAA
ProCare Therapy Services
480 Reservoir Ave.
Cranston, RI
401-270-2500



SPEECH THERAPY

BrownHealth Rehabilitation Services
765 Allens Ave, Suite 102
Providence, RI 02905
401-444-5418

BrownHealth Rehabilitation Services
195 Collyer Street Suite 301
Providence, RI 02906
401-793-4080

Spaulding Outpatient Center at Kent Hospital | East Greenwich
1351 South County Trail
Building 2
East Greenwich, RI 02818
401-886-4650

Sargent Rehabilitation Center
(up to age 22)
800 Quaker Lane, Warwick, RI 02818
401-886-6600

Aphasia Center
MGH Institute of Health Professions
2 Constitution Wharf
Charlestown, MA
https://mghihp.formstack.com/forms/ipc_client_services_inquiry_form

LEGAL ASSISTANCE

MASSACHUSETTS



HYMAN DARLING, CELA

Bacon Wilson, PC

Specialty: Estate Planning
33 State Street
Springfield, MA 01103
Tel: (413) 781-0560
Fax: (413) 739-7740

MEREDITH H. GREENE, ESQ.

Day Pitney LLP

Specialty: Special Needs Trusts, Estate Planning, Guardianship, Conservatorship
One Federal Street, 29th Floor
Boston, MA 02110
Tel: (617) 345 4622
Fax: (617) 607 6033

KEN W. SHULMAN, ESQ.

Day Pitney LLP

Specialty: Estate Planning, Special Needs Trusts
One Federal Street, 29th Floor
Boston, MA 02110
Tel: (617) 345-4789
Fax: (617) 206-9357

DANIEL SURPRENANT, CELA

Surprenant & Beneski, P.C.

https://myfamilyestateplanning.com
35 Arnold Street
New Bedford, MA 02740
Tel: (508) 979-0975

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Mulvena Winston, PC

neal@mulvenawinston.com
2 Main Street, Suite 350
Stoneham, MA 02180
https://winstonlg.com/
Tel: 781-288-4100
Fax: 781-791-4606

RHODE ISLAND

MARK B. HEFFNER, CELA

Heffner & Associates

mheffner@hefflaw.com
615 Jefferson Boulevard
Warwick, RI 02886
Tel: (401) 737-1600.
Fax: (401) 737-1652

AMY STRATTON

mail@MoonanStratton.com
4 Richmond Square, Suite 150
Providence, RI 02906.
(401) 272-6300

HD EXPERIENCE

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https://kecheslaw.com/injury-attorneys/
Phone: 508-500-1188

ALLISON BARTLETT, ESQ.

abartlett@hdsa.org
Senior Manager, Disability Programs
HDSA

OTHER LEGAL HELP

MA BAR REFERRAL SERVICE

(866) 627-7577

RI BAR REFERRAL SERVICE

(866) 627-7577

MA LEGAL RESOURCE FINDER

https://masslrf.org/en/home

RI LEGAL SERVICES

https://rils.org/

SOCIAL SECURITY DISABILITY ASSISTANCE



What if I become disabled due to my disease?

The HDSA has a lawyer on staff; she is the only one in the country who specializes in HD and applications for HD patients. Allison Bartlett, Esq - abartlett@hdsa.org
It is a good idea to understand the process and what is needed BEFORE starting your application. A good first step can be to review the following and contact Allison: https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/disability-support/

1 The first step in apply for disability or federal aid is understanding the program that you need. The Social Security Administration has two disability programs which are federally funded. They are often confused because they have many similarities and some important differences. These programs are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

You can apply online: https://www.ssa.gov/onlineservices/
Call: Toll-Free: 1-800-772-1213

2 If need further assistance you can go to a local office. There are multiple IN PERSON locations throughout Massachusetts and RI; **follow the link to find an office close to your home.**
https://secure.ssa.gov/ICON/main.jsp#officeResults

Disability help guide for getting started:
Adult:https://www.ssa.gov/disability/Documents/Adult%20Disability%20Starter%20Kit%20508%20English%209.25.23.pdf

Child: https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

Important things to include in your DISABILITY application to avoid being denied: Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits. These conditions primarily include certain cancers, adult brain disorders, and a number of rare disorders that affect children. This initiative helps us reduce waiting time to reach a disability determination for individuals with the most serious disabilities.

Huntington's disease is also discussed in the Social Security Administration's "Blue Book" listing of disabling conditions in two different sections. The physical aspects of the disease are discussed in Section 11 (Neurological Disorders) under paragraph 11.17 (Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration). When an applicant is suffering primarily from mental or cognitive effects of Huntington's Disease, they may be instead evaluated according to the listing in paragraph 12.02 (Neurocognitive Disorders).

Below is information for compassionate allowance, please be sure to include this information when applying for disability. Impairment Evaluation Criteria Huntington's disease is on the Compassionate Allowance List and falls under the following section. This must be added to your application.

Section 11.00 – Neurological Disorders o 11.17 Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration.

For a complete how to guide visit this website:
https://health.ucdavis.edu/huntingtons/files/How_to_File_for_Social_Security_Disability_What_You_Need_to_know[2].pdf

Caution: HD diagnosis is not enough to be considered disabled. Social Security is evaluating your functional ability as it relates to your ability to work and care for yourself.
Caution: There is still a 24-month holding period of Medicare even if criteria is met for disability.



THE LONG-TERM CARE CHALLENGE



Finding placement for a loved one in long term care that specializes in HD is limited. Please use the attached resource guide to provide to staff members and family to help them understand the disease. *Additionally, you can contact the local social worker for assistance in education the long-term care facility you chose for your loved one.*

MA/RI HDSA Social Worker
Kelsey Muttiah LCSW
kmuttiah@hdsa.org
Phone: 518-557-8041

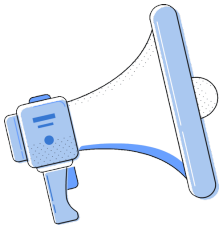
Caregiver resource guide to provide to facilities: https://hdsa.org/wp-content/uploads/2015/04/CaregiverGuide_Mid_Late_StageHD.pdf

Search for HD facilities here: https://hdsa.org/about-hdsa/locate-resources/
Below is a list of long-term care facilities who report experience with HD patients.
This is not an endorsement of any mentioned facilities; note that not all facilities take Medicaid.

Facility	Address	Contact
Eleanor Slater Hospital (State Hospital)	2090 Wallum Lake Rd. Pascoag, RI 02859	401-567-5400
Tewksbury Hospital (State Hospital)	365 East St Tewksbury, MA 01876	(978-851-7321
CareOne Lowell	19 Varnum St. Lowell, MA 01850	(978-454-5644
Fresh River Healthcare	96 Prospect Hill Rd. East Windsor, CT 06088	860-623-9846
Incompass Human Services (group home)	Tyngsboro, MA	978-349-3000 (MA ABI MFP Waiver Only)
Western Mass Hospital (State Hospital)	91 E. Mountain Road Westfield MA 01085	(413-562-4131

ADVOCACY/RESEARCH

SIGN UP



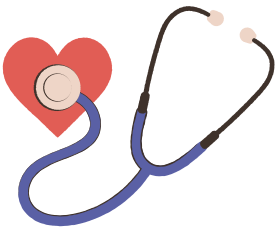
Action & Advocate

hdsa.org/advocacyhome/TakeAction/



Research Projects

hdsa.org/hd-research/learn-about-hd-research/



Clinial Trials

app.emergingmed.com/hdsa/home

Additional Numbers To Get Involved

- Helpline: 800-345-HDSA (4372)
- National Office: 212-242-1968
- Email: HDSAinfo@HDSA.org

Advocate: HD Parity Act

The HD Parity Act will waive the two-year Medicare waiting period, as well as waive the 5-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI). Medicare's two-year waiting period is particularly devastating for people with HD.

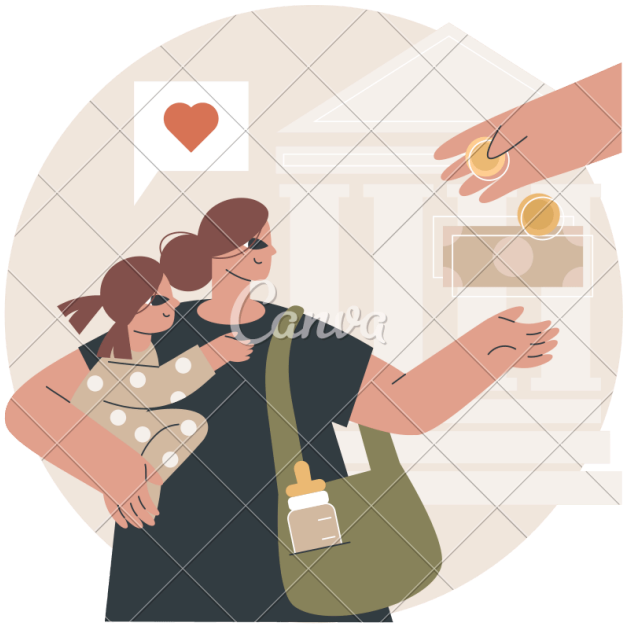
https://hdsa.org/about-hdsa/advocacy/huntingtons-disease-parity-act-2/

Disability Advocacy/Rights

- Disability Rights Rhode Island: drri.org/
- Disability Law Center – Boston: www.dlc-ma.org/
- Centers for Independent Living : Peer support, advocacy, info/resources, assessments
- Ocean State Independent Living (Rhode Island): www.oscil.org/
- Independent Living Centers (Massachusetts, by location): www.mass.gov/independent-living-centers

GRANTS & FINANCIAL ASSISTANCE

All Ages	Children & Young Adults	Children with Medical Needs
Selma Schimmel Vital Grant www.vitaloptions.org/assistance	**Ellie's Army** elliesarmy.org/apply-for-assistance/	**Guidance Medical** guidancemedical.org/
		Aubrey Rose Foundation aubreyrose.org/financial-assistance-for-families/
Chive Charities chivecharities.org/recipient		**B Brave Foundation** bbravefoundation.org/
		United Healthcare Children's Foundation uhccf.org/
		Oracle Health Foundation oraclehealthfoundation.org/pediatric-grants



VIRTUAL SUPPORT GROUPS

Group	Phone	Email
Third Saturday of the month - Caregiver only at 9:00 AM - 10:00 AM	978-317-2691	mirtas.ulivi@gmail.com
Third Saturday of the month - Mixed group at 10:30 AM - 12:00 PM	978-317-2691	mirtas.ulivi@gmail.com

Additionally, you can contact the local HDSA social worker for information on upcoming groups.

MA-RI Social Worker Kelsey Muttiah LCSW	508-446-7705	kmuttiah@hdsa.org

STATE PROGRAMS - CONNECTIONS TO SERVICES

Office of Rehabilitation Services - RI	ors.ri.gov
MassAbility - MA formerly known as Mass Rehabilitation Commission	mass.gov/orgs/massachusetts-rehabilitation-commission

BRAIN DONATION



The Harvard Brain Tissue Resource Center (HBTRC), established at McLean Hospital in 1978 and known as the Brain Bank, is a centralized resource for the collection and distribution of human brain specimens for brain research. The Brain Bank collects brain and tissue samples from across the United States and distributes them to investigators all over the world.

Daytime Contact (8:30am-5pm EST)
Phone: 617.855.2400
Fax: 617.855.3199
Email: HBTRC@mclean.harvard.edu

After Hours Contact (5pm-8:30am EST)
Phone: 800.BRAINBANK (800.272.4622)
Fax: 617.850.8711
Email: HBTRC@mclean.harvard.edu

MEDICAL

Medicaid-Funded Non Emergent Medical Transportation

Programs to assist patients with getting back and forth from medical appointments.

Rhode Island	Massachusetts
MTM https://www.mtm-inc.net/rhode-island/	**PT-1 (through GATRA or MART)** https://www.mass.gov/info-details/get-a-ride-to-masshealth-medical-appointments

Medication Savings & Copay Relief

Good RX https://www.mtm-inc.net/rhode-island/ • Compare coupon savings versus insurance copay (cannot use together with insurance) • Call your pharmacy to make sure they accept GoodRX coupons	**CostPlus Drugs** https://costplusdrugs.com • Compare savings versus insurance copay (cannot use together with insurance)
SingleCare https://www.singlecare.com/ • Compare coupon savings versus insurance copay (cannot use together with insurance) • Call your pharmacy to make sure they accept SingleCare coupons	**NeedyMeds** https://www.needymeds.org/pap • Search for coupons for medications, as well as manufacturer discount applications
Patient Advocate Foundation (HD Fund for All Insurances is Currently Closed but Will Reopen) https://copays.org/funds/	**Healthwell Foundation** (HD Fund for Medicare is Currently Closed but Will Reopen) https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/

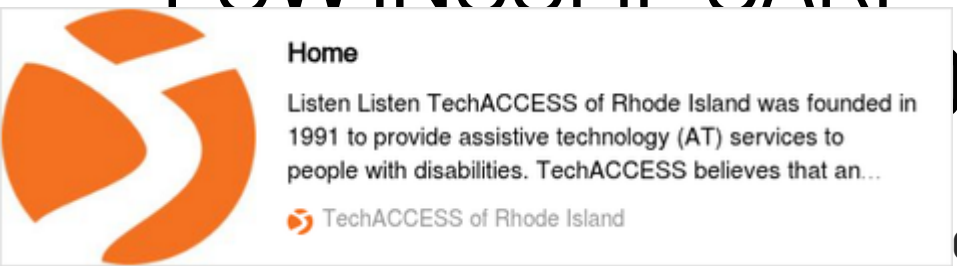
MEDICAL

Medically-Tailored Meal Delivery

Community Servings
https://www.servings.org/

- Must be mostly homebound
- Massachusetts and Rhode Island - most areas
- Has Waitlist

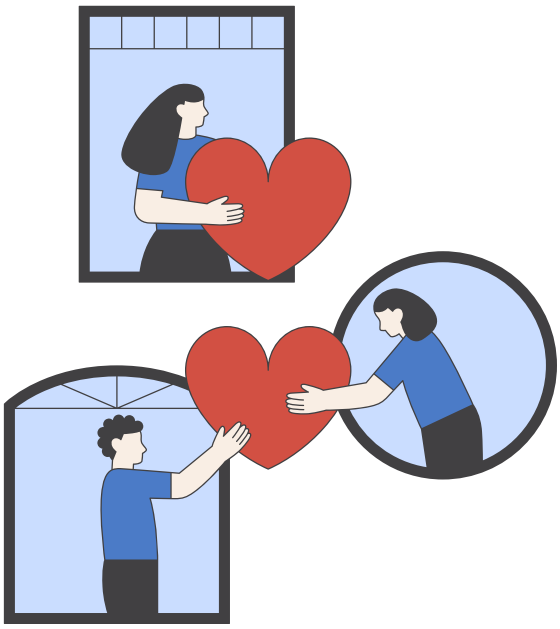
LOW INCOME CARE



OUNDATION

Enteral Supply Donation Program

https://oley.org/page/Copy_Equipment_Exchange



DYSPHAGIA OUTREACH PROJECT

Dysphagia Food Bank

https://www.dysphagiaoutreach.org/foodbank

DME/REEQUIPMENT

Durable Medical Equipment

Massachusetts-based

https://dmereuse.org/

GETATSTUFF

Assistive Technology

Massachusetts-based

https://getatstuff.massmatch.org/

TECHACCESS RI

Assessment and Device Loan Program

Rhode Island Only

https://www.techaccess-ri.org/

Disclaimer: This information is not legal advice and is not preferential to any organization. HDSA MA/RI does not recommend any of these facilities, and proper research should be done prior to the use of these resources. This information is always subject to change. Please contact: ldiveglia@hdsa.org to add any additional resources or with comments on resources you would like to see included.